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Effectiveness of behavioral programming and the traumatic brain injury waiver program: a caregiver's perspective.

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MASTERS IN SOCIAL WORK THESIS

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Effectiveness of Behavioral Programming and the Traumatic Brain Injury Waiver Program: A Caregiver's Perspective

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Effectiveness of Behavioral Programming and the Traumatic Brain Injury Waiver Program: A Caregiver's Perspective

by

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Dedication

To my parents who instilled the value of education and encouraged me throughout my graduate studies.

To my nieces Brooke and Megan for reminding there is always time for laughter and play.

To caregivers everywhere for your endless dedication to individuals with brain injuries and the many sacrifices you have made along the way.

ABSTRACT OF THESIS

EFFECTIVENESS OF BEHAVIORAL PROGRAMMING AND THE TRAUMATIC BRAIN INJURY WAIVER PROGRAM: A CAREGIVER'S PERSPECTIVE

WENDY S. WALKER
May, 1996

The purpose of this exploratory study is to determine the effectiveness of behavioral services offered to adults, ages sixteen to sixty-five, through the Traumatic Brain Injury Waiver Program (TBIW). This community-based program provides the level of behavioral services previously only available to institutionalized individuals. 21 identified primary caregivers were sent a questionnaire consisting of qualitative and quantitative questions to assess their perceptions and understanding of the services provided. Discussion focuses on a comparison of the research findings in relation to existing literature. Implications for the social work practice include the need for ongoing education and community support for individuals with Traumatic Brain Injuries (TBI), as identified by their primary caregivers.

Table of Contents

To laugh often and love much;

to win the respect

of intelligent persons

and the affection of children;

to earn the approbation

of honest critics

and to endure the betrayal

of false friends; to

appreciate beauty;

to find the best in others; to

give of oneself;

to leave the world a bit better

whether by a healthy child,

a garden patch, or a

redeemed social condition;

to have played and laughed with enthusiasm

and sung with exultation;

to know that even one life

has breathed easier because you lived....

this is to have succeeded.

RALPH WALDO EMERSON

EFFECTIVENESS OF BEHAVIORAL PROGRAMMING AND THE TRAUMATIC BRAIN INJURY WAIVER PROGRAM: A CAREGIVER'S PERSPECTIVE

I. INTRODUCTION

In Minnesota more than 10,000 individuals sustain traumatic brain injuries (TBI) each year with 1,000 suffering moderate to severe injury (Minnesota Department of Human Services, 1992). Traumatic brain injury is defined as a sudden insult or damage to the brain or its coverings from an external force, not degenerative or congenital in nature. The insult or damage may produce an altered state of consciousness and may result in a decrease in cognitive, behavioral, emotional, or physical functioning resulting in partial or total disability (Minnesota Department of Human Services, 1990). Nationally it is estimated that over 1,000,000 incidents occur annually, thus becoming one of the most rapidly growing disabilities in the United States (Minnesota Department of Human Services, 1994). The majority of victims are males between 15 and 24 years old with life expectancies of an additional 35 to 50 years. Trauma is the leading cause of death for individuals younger than 35 years, with head injuries accounting for approximately 65% of annual trauma injuries (Mackay, Berstein, Chapman, Morgan, & Milazzo, 1992). In 1993, 4,000 hospital admissions and 800 deaths in Minnesota were attributed to traumatic brain injuries as noted in the Minnesota Department of Health Traumatic Brain Injury/Spinal Cord Registry (Minnesota Department of Human Services, 1994).

People are affected by traumatic brain injuries in many facets of life including physical , emotional, neuropsychological, and social impairment (Klonoff, Lage, & Chiapello, 1993). In fact, approximately 90% of persons with a traumatic brain injury manifest some type of permanent cognitive, behavioral-emotional, and/or physical impairment in varying degrees of severity (Minnesota Department of Human Services, 1994). The most difficult task is aiding clients and their families, or significant others, in setting realistic goals for the future. Notable and often irreversible changes in personality, temperament and memory occur in the brain injured individual, causing considerable stress for the client and his/her support network (Klonoff, et al., 1993).

Long term needs for traumatic brain injured individuals will vary according to the individual level of recovery, dependency, living situation, support systems and resources (Beals, Matthews, Elkins, & Jacobs, 1990). A needs assessment conducted by the Kansas City Head Injury Association indicates that people in institutional settings have the following needs: special therapies: (e.g., occupational and physical therapy), cognitive retraining, community residences, age-appropriate long term care facilities and transitional residential programs. For individuals living in the community, transportation was often not available and not affordable for people living alone. Beals et al., 1990, found that case management services were identified as vital to individuals with brain injuries/families apprised of services in the community. Personal and family advocacy was noted as an important source of education for legislators and their staffs regarding the special needs of individuals with head injuries. Other

II. HISTORY OF THE TBIW PROGRAM

Traumatic Brain Injury Waiver Program Development

The Traumatic Brain Injury Home and Community Based Waiver (TBIW), developed by the Minnesota's Department of Human Services in 1992, was created to provide a home and community based service waiver to allow community alternatives for survivors of brain injury who were experiencing significant behavioral, emotional, or cognitive problems related to their injury across Minnesota. Prior to 1992, individuals with severe traumatic brain injury with severe behavioral problems resided in a nursing home or neurobehavioral hospital due to prohibitive costs of providing physical and behavioral needs in the community (Minnesota Department of Human Services, 1992).

In implementing this program six regional case resource specialists and offices were created to meet the needs of Minnesotans statewide (see figure 1)(Minnesota Department of Human Services, 1995). The current study focused on the TBIW Program in Hennepin County.

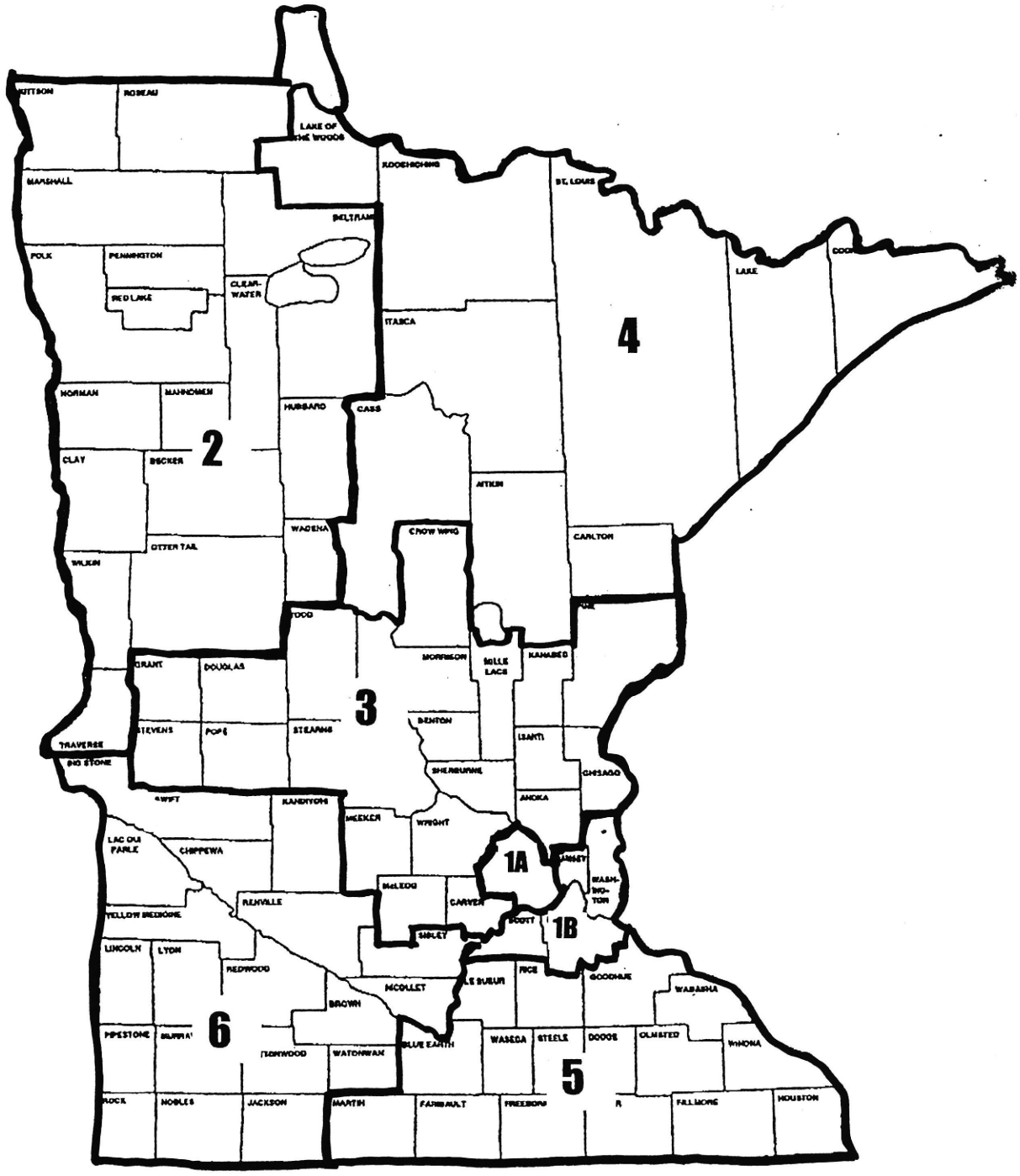

Fig. 1. Minnesota regional distribution of TBIW Programs statewide

Due to the comprehensive and unique services needed by survivors of traumatic brain injury to avoid institutionalization, the Department of Human Services submitted an application for a Traumatic Brain Injury Home and Community Based Waiver to the Health Care Financing Administration (HCFA) in December 1991. Approval was received and the program became effective May 15, 1992 (Minnesota Department of Human Services, 1992). For an applicant to be eligible for services he/she must:

1. Have a diagnosis of traumatic brain injury that is not degenerative or congenital.

2. Be at risk of institutionalization due to significant behavior/emotional, or cognitive problems that are related to the brain injury.

3. Be under the age of 65 (Individuals are eligible for the TBI Waiver until the end of the month in which they have their 65th birthday).

4. Be screened by the county preadmission screening (PAS) team.

5. Currently be residing in a nursing facility or require nursing facility level of care as determined by the PAS team.

6. Be certified disabled by the State Medical Review Team (SMRT) or the Social Security Administration.

7. Be eligible for Medical Assistance (MA) based only on the person's income and assets (deeming waiver applies) and/or be eligible for MA with a spenddown(spend excess monies/assets in accordance to MA guidelines to pay privately for a portion of services provided to eventually reach the designated dollar amount that would declare an individual eligible for MA).

8. Choose community care , and in order to remain in the community, require services which exceed those available through MA and are not available through other sources of funding. The TBI Waiver is a waiver of "last resort". The client must be unable to receive adequate services under other home and community based service waivers

9. Be able to receive home and community care services at a cost to MA that will not exceed the MA expenditure to maintain the individual in a

nursing facility (as cited in Minnesota Department of Human Services, 1992 Publication No. #92-57B, pp. 2-3).

Traumatic Brain Injury Waiver Services

Various services were provided under the auspices of the Waiver program (Minnesota Department of Human Services, 1992). Comprehensive services are provided through the Waiver to allow services for individuals with traumatic brain injuries to be provided in a home environment(see appendix B for current services available through the TBIW).

Traumatic Brain Injury Legislative Background

Forces were at work over the past decade to create the current TBI Waiver program (Minnesota Department of Human Services, 1994). In 1985 the Minnesota Legislature mandated the Department of Human services(DHS) to establish a Task Force on needs of persons with brain injuries and submit recommendations to the Commissioner of DHS. In 1989 the Minnesota legislature passed the " Services for Persons with Traumatic Brain Injury " legislation which mandated DHS to take a lead role in coordinating and supervising health care services affecting individuals with traumatic brain injuries (Minnesota statue c 282 art 3 s 62). It also developed an administrative case management system for Medical Assistance eligible survivors to assure appropriate, accessible cost effective services through Medical Assistance as a means of preventing institutionalization.

In 1991 the " Services for Persons with Traumatic Brain Injury " legislation was revised to include a DHS Advisory Committee. In 1991 the Minnesota Legislature also passed the " Traumatic brain Injury and Spinal cord Registry " which mandated Minnesota's Department of Health to establish and maintain a central registry of persons who sustain a traumatic brain injury or spinal cord injury (Minnesota statue 144.662). The purpose of the registry was to collect information to aid in the development of injury prevention, treatment and rehabilitation programs, and to ensure the provision of information about public or private agencies that provide services to individuals with traumatic brain injury and spinal cord injury (Minnesota Department of Human services, 1994).

Department of Human Service's Task Force

The Department of Human Services' Task Force was established in 1993 to facilitate communication and coordination of policy and services, and develop statewide divisions. The Task Force's role was envisioned to assist programs and state agencies to identify gaps in services and provide formal policy recommendations to the Commissioner of Human Services. The purpose was also to identify the unique needs of individuals with traumatic brain injury and adapt current means of providing service(s) (e.g., case management, rehabilitation needs, employment issues, and chemical dependency needs, and specialized training for caregivers and professional staff regarding the needs of individuals with brain injuries).

Traumatic Brain Injury Waiver (TBIW) Program Update

In response to the Task Force's recommendations and legislative changes, the TBIW was modified in May 1995 to incorporate the recommendations by developing a comprehensive case management program and establishment of neuropsych services in the community versus institutional setting (Minnesota Department of Human Services, 1995). A portion of the individuals who could benefit from other services available through TBIW, also required a more intense level of care due to their severe behavior deficits. However these individual's behavior(s) were placing them at risk for institutionalization, as these behaviors were deemed unmanageable for most community settings. In 1993, a neurobehavioral hospital was opened in Minnesota (Bethesda Lutheran Hospital's Neurobehavioral Unit in St. Paul, MN), to identify and treat such aggressive behavior concerns. The Department of Human Services (DHS) amended the TBIW to allow for community-based services for individuals with severe traumatic brain injuries and severe behavior problems to be cared for in a community setting. The TBIW now has two levels of care available: TBIW-NF for persons who require the level of care available in a nursing facility (NF); and TBIW-NB for persons who require the level of care available in a neurobehavioral (NB) hospital.

To be eligible for the program a person must meet the eligibility criteria for both nursing facility and neurobehavioral hospital levels of care. The first screening is the assessment specific to NF level of care(see appendix C); the second assessment is specific to NB level of care (see appendix D) (Minnesota

Department of Human Services, 1995). To qualify for the TBIW program, the individual applicant must:

1. Have a diagnosis of traumatic brain injury that is not degenerative or congenital.

2. Be at a level IV or above on the Ranchos Los Amigos Levels of Cognitive Functioning. (The Rancho scale is used nationally to assess cognitive status. Generally, levels I to III are considered states of coma. Level IV persons may have the potential to benefit from rehabilitation. At a level IV, the individual is in a heightened state of activity with a severe decreased ability to process information. Behavior is nonpurposeful relative to the immediate environment. (Attempts to climb out of bed, remove restraints, and hostility are characteristic of this population.) The individual requires maximum assistance to perform self-care activities. An individual may sit, reach, or walk, but will not necessarily perform these activities upon request (Minnesota Department of Human Services, Attachment A, 1995).

3. Be under the age of 65 when the waiver begins.

4. Be certified disabled by the State Medical Review Team (SMRT) or the Social Security Administration.

5. Be eligible for Medical Assistance (MA) based only on the applicant's income and assets.

6. Choose community care and, in order to remain in the community, require services which exceed those available through MA and which are not available through other sources of funding.

7. Be able to receive home and community services at a cost to MA that will not exceed the MA expenditure to maintain an individual in a nursing facility or neurobehavioral hospital.

8. Be determined eligible by DHS staff based on the TBI Waiver Application Supplement (Department of Human Services, 1995. pp. 2-4).

Mission Statement

As the TBIW program is one of five programs administered by Hennepin County's Community Health Department's Community-Based Long-Term Care

(CBLTC) Program, a separate mission statement and goals were developed. The mission of the CBLTC program is as follows: " To assist functionally impaired residents of Hennepin County and their families in making wise decisions about their long-term care options and to assist them in using community based long-term care services " (Hennepin County Community Health Department, 1993, p 2).

The goals of CBLTC were to :

1. Provide information to functionally impaired people and their families via face-to-face interviews, telephone screenings and/or whatever means necessary to assist clients in making informed choices regarding their health care needs.
2. Provide services to eligible persons to avoid unnecessary institutionalization.
3. Purchase needed services from private vendors to provide individuals with quality services in a cost effective manner.
4. Provide quality services to clients and their families in the process of implementing the state mandated CBLTC Programs.
5. Provide feedback or propose changes to the CBLTC Programs in order to improve the efficiency and effectiveness of the programs.

III. A REVIEW OF THE LITERATURE

Models of Rehabilitation

The following models of rehabilitation discussed will review the changing philosophy of the medical profession to identify alternative means of providing rehabilitation to individuals with traumatic brain injuries, both on inpatient and outpatient levels. In some cases the rehabilitation process will continue years after their initial injury (Klonoff, et al., 1993). Over the past decade all levels of injury, from minor bumps to severe injuries have gradually been given the same degree of priority in management of individual's care needs (Wehman, et al., 1993).

Medical Model

The majority of literature on traumatic brain injury (TBI) rehabilitation focuses on efforts to assist those individuals who have sustained a mild to moderate traumatic brain injury and may benefit from rehabilitation efforts. Although these individuals often have various deficits (e.g., memory problems, personality change, etc.) these individuals are able to return to their home and families to continue their rehabilitation and their lives with the guidance of rehabilitation professionals (Mills, Nesbeda, Katz, & Alexander, 1992; Klonoff, et al, 1993; Moore & Stambrook, 1995). The medical model, where the "medical experts" guide the patient and his/her family through the rehabilitation process, allows

the patient to become part of the team as discharge plans become finalized. This model is predominate in rehabilitation settings today.

A Model TBI System of Care

An extension of the medical model, this model program was initiated in 1987 through funding made available by the National Institute on Disability and Rehabilitation Research, US Department of Education. This demonstration program provides 5 model systems for the care of traumatic brain injured individuals. The purpose of this project was to provide a coordinated continuum of care from the onset of injury when emergency medical services initially intervened to the development of the treatment plan upon discharge. Services provided include: inpatient and/or outpatient rehabilitation programs(including physical, psychological, vocational and social services) and long-term interdisciplinary follow-up to ensure optimal community integration (Ragnarsson, Thomas, & Zasler, 1993). Each model system also established an injury prevention program, provided educational opportunities for professionals and the general public, and conducted research to demonstrate the effectiveness and benefits from these interventions.

Interdependent/Empowerment Model

The study of individuals with traumatic brain injuries has been guided by the medical /expert model but concern has developed that this model has fostered dependency in patients since decisions are often determined by the

physician (Condeluci, 1992). The interdependent/empowerment model addresses the need to empower patients re-entering the community to actively participate in their lives. This is accomplished by building a bridge between the medical paradigm that initially causes dependence on the medical expert to the interdependent/empowerment perspective that returns the power of choice to the individual during the latter stages of rehabilitation to plan for long term needs.

Whatever It Takes Model

The medical/rehabilitation model has been further expanded by Willer and Corrigan's (1994) Whatever It Takes model (WIT), providing community-based services for individuals with traumatic brain injuries. WIT attempts to adapt practices carried out in the rehabilitation setting to a non-medical approach in the community. This model proposes that self-determination is the desired goal for individuals with traumatic brain injuries, but the model recognizes the fact that cognitive and behavioral deficits will interfere with the options available and the person's ability to make informed choices. Therefore, individuals are encouraged to participate to the maximum of their ability. The model also proposes that community integration will require existing community services to be utilized to their fullest prior to creating any new additional services. Often services can be modified to meet the needs of individuals with traumatic brain injuries. This approach provides a practical and innovative means for program development and interventions.

Community Integration

For individuals with significant cognitive impairment in addition to severe behavioral difficulties, limited research is available regarding program options available in the community (Shue, 1993). These individuals are often in need of 24 hour care which is difficult for family members to provide given the lack of community resources and availability for long term support for individuals and their families.

The Repatriation Community Programs pilot project was funded in 1990 by the Ontario Provincial Ministry of Health. It required all individuals who had gone to the United States for rehabilitation be returned to their home communities in Ontario. The goal was to provide community-based services as well as create a service delivery system and interagency collaboration that could be implemented in other providences (Shue, 1993). Ten individuals were selected for the project. Results of the study found that current hospital and community-based day programs were not able to provide services to the severely impaired individuals due to staff limitations. Also, additional funding was not available for individuals with lower cognitive functioning or those with severe behavior disabilities. Thus, it was recommended that more community resources be available in a cost-efficient manner. The Whatever It Takes (WIT) model (Willer et al., 1994), as discussed earlier also provides a community-based service model that is geared toward the individual's needs and severity of brain injury.

Few service models address long-term community living for individuals with severe brain injury. The Transitional Living Centre of Kingston, Ontario, (KLTC) a community based post-acute rehabilitation program, provides both residential and day programs for brain injured adults in addition to providing support and education for their family members (Harrick, Krefting, Johnston, Carlson, & Minnes, 1994). Three guiding concepts of the program are: 1) importance of self-awareness to adapting to community life; 2) the use of compensatory strategies; and 3) modification of physical and social environment to reduce impact of disability. Specialized programs are available in group sessions, individual training and counseling which may include: memory/orientation training, life skills, social skills, substance abuse, behavioral programs, and recreational activities. The average length of stay in the residential program is 6 months(Harrick et al., 1994).

To determine the success of functional outcomes on a long-term basis, 21 individuals (16 males and 5 females) with severe traumatic brain injuries were studied from admission to the acute rehabilitation program, 1, and 3 years post-discharge. The average age on admission to the program was 25.8 years. Functional status of brain injured individuals was measured by participation in productive activity, financial support, place of residence, and level of supervision required (Harrick et al., 1994). Results of the study found improvements in functional status at 1 year remained stable or improved at the 3 year follow-up. Loneliness and depression, although not reported on

admission to the program, increased over time, to become the two problems most frequently reported in the 3 year follow up. The prevalence of loneliness and depression found at post-discharge demonstrated the need for community support and highlighted the emotional and social vulnerability of survivors' severe brain injury even when functional improvements are achieved (Harrick et al., 1994).

Racino and Williams (1994) note the importance of the brain injured support network in community integration. The authors stress the need for everyone involved with the brain injured individual to actively be involved in the change process (current level of functioning versus pre-injury status) to assist individuals to fully readjust to community living. This requires businesses and agencies that serve individuals with disabilities , such as independent living centers, to move toward the inclusion of individuals with cognitive disabilities, such as persons with traumatic brain injuries. Professionals, agencies, and universities will also need to find creative means to be more responsive to desires and needs of people with brain and/or other cognitive impairments.

Case Management Services

Many authorities feel the term "case management" is difficult to define (Austin, 1990). This is because the definition changes in accordance to the type of clients being serviced as well as the scope of services provided. Amado, McAnally, and Linz (1989) state the following factors are particularly important in defining a case management system: (a) the nature of the client

population to be served; and (b) the nature of the existing service system. They state these factors are key in creating the structures, functions, and goals of a given case management system. Clients deemed appropriate for case management services are those with multiple problems and needs that are unable to define, locate, or secure necessary services and who lack the resources to perform these function(s) on an ongoing basis.

The idea of case management has been a constant theme with the TBI population (Austin, 1990). Depending on the setting, the case manager may be a separate position or may be incorporated into the social worker's or other team member's job description (Roach, 1993). Case management services are defined differently, depending upon the case manager or the setting where the individual resides. It is necessary for the case manager to educate consumers and their families regarding available resources and the process that must occur to receive requested services. The overall goal of case management is to increase the knowledge base of the client and their support system to enable the client to have more control over their lives.

Austin (1993) notes that the community-based long-term care programs, which enable disabled individuals to remain at home by providing home-care services, are a recent phenomenon within case management. However, these programs are limited due to funding concerns but were originally created to provide a broad range of services to clients in the home setting in a cost efficient manner. Dixon, Goll & Stanton (1988) reiterate Austin's findings. These

authors comment that due to the complexities and costs involved with head injury rehabilitation, the industry will need to continue to create alternative models and levels of care to create a case management concept that is both cost effective and beneficial to brain injured individuals.

Vocational Opportunities

Because of the current lack of incidence and prevalence statistics, it is difficult to determine the number of individuals with traumatic brain injuries who require vocational rehabilitation services or maintain gainful employment (Courtney, 1994). Since 1987 the Minnesota Department of Jobs & Training-Division of Rehabilitation Services (DRS) has recognized that TBI individuals represent an underserved population. The challenges to employment faced by these individuals are complex and variable. DRS has placed an emphasis on collaborating efforts with consumer and advocacy organizations and providers of rehabilitative services. As part of this collaborative effort, DRS in conjunction with the Minnesota Head Injury Foundation Association, have been the recipient of two Federal Research and Demonstration Grants in the area of community supports and supported employment services to individuals with TBI to explore alternative programs to meet the long-term employment issues facing individuals with severe traumatic brain injures, in addition to severe behavioral problems (Courtney, 1994).

Traumatic brain injury has a dramatic impact and long-term consequences affecting all aspects of a person's life, including cognitive,

physical, psychological, social impairments, in addition to affecting the TBI individual's employability (Lubusko, Moore, Stambrook, &Gill, 1994). Our society places a high value on people who are productive and who actively contribute to society. However due to the degree of injury in individuals who sustain severe trauma to the brain many post-TBI individuals are unable to return to work or are forced to work at a lower status and with less demanding jobs. Several factors have been identified that predict a person's vocational outcome. Lower post-injury occupational status has been positively associated with TBI severity, as indicated by a lower Glasgow Coma Scale (GCS) scores on admission to the hospital, longer lengths of post-traumatic amnesia (PTA) and longer duration of coma. Lower post-injury occupational status has also been related to patient care, lower pre-injury vocational status, and the presence of cognitive, physical and psychosocial difficulties.

An exploratory study evaluating the cognitive beliefs of 19 severely traumatically brain injured males were assessed to determine their relationship with post-injury employment status (Lubusko et al., 1994). Individuals who had sustained severe brain injuries and had participated in a rehabilitation program between 1981 and 1987 in Manitoba, Canada, were included in the study. Individuals' vocational status was measured by the Blishen quantitative social economic index, which was modified to incorporate individuals who were homemakers, retired, unemployed or students at the time of their injury. Cognitive belief variables were measured by having the participants complete the following scales: the Multidimensional Health Locus of Control Scale

(MHLOC), the Revised Internal-External Scale (RIES), and the Beck Hopelessness Scale (BHS). Findings indicate that negative cognitive beliefs may be associated with decreased post-injury employment status. These findings are consistent with the existing literature linking low employment status and unemployment with external attributions, feelings that life events are beyond personal control, and depression.

Young adults who were severely brain injured were studied 2 years after completion of rehabilitation at Wolfson Medical Rehabilitation Centre in Wimbledon, London, to track their social adjustment (Weddell, Oddy, & Jenkins, 1980). Issues of returning to work were addressed in the study. Only 5 of 44 individuals were able to return to their former jobs, and did so after absences of 6 months or more. Two of those held unskilled jobs, 2 were skilled manual workers and 1 was a teacher. In addition 3 individuals had fully resumed their roles as homemakers and were said, by their husbands, to cope with their duties adequately. Eleven individuals held full-time jobs but were working in a reduced capacity. They resumed work 6-18 months after their accidents. Although a few individuals had been given alternative jobs in their old firm, most (n= 8) had to find work elsewhere and had often attempted a series of different jobs. Three individuals had spent short periods in one or more jobs and 2 were able to work only on a part-time basis. Twenty individuals were unable to work at all. These individuals (n= 20) were attending day activity centers or spent most of their time at home (Weddell, et al., 1994).

Wehman et al., (1993) studied investigated a sample of 39 individuals returning to work program at the Department of Physical Medicine and Rehabilitation in Richmond, Virginia. The program emphasized a supported employment approach to identify key functional characteristics which differentiated successful and unsuccessful individuals. are notes of those patients who participated in the follow-up study unemployment rates soared post-injury . Wehman and others noted in past studies unemployment for individuals with severe traumatic brain injury stayed at very high rates of 50-80% for long periods of time, even with vocational rehabilitation intervention. Wages were also significantly reduced from pre-injury levels and there is tremendous turnover in employment among post-injury clients (Wehman et al, 1993). The authors developed a supported employment program with the provision of intense one-to-one training, counseling, and advocacy services. A skilled employment specialist assisted brain injured individuals directly on the job site versus learning skills in the sterile environment of a sheltered workshop. Ongoing support services were provided throughout the course of the individual's employment.

Findings indicated that clients identified as the least difficult(easier to locate employment, followed directions, could often work independently, and had minimal to no behavioral problems), were 10 years older at the time of placement and less likely to be recipients of Social Security disability benefits than those identified as the most difficult(had significant difficulties following directions, working independently or with others, and had difficulty with

behavior outbursts on the job) (Wehman et al., 1993). Members of the most difficult group waited twice as long as the least difficult group for employment opportunities. Earnings for this group(difficult) were significantly lower ($ 4.61 per hour versus $ 4.93 for individuals identified as the least difficult). Individuals in the most difficult group were twice as likely to be involuntarily terminated from employment than persons on the least difficult group(46.2 versus 20.0). In addition, employment specialists spent more than twice as much staff time and resources on individuals who clients who had inferior outcomes in comparison to the less difficult group. Thus employment programs need to be aware of varying rates of work productivity of severely brain injured individuals, dependent on their cognitive and behavioral deficits (Wehman et al., 1993) .

In a contrasting study, working capacity, annual income and sick leave 5 to 8 years after severe traumatic brain lesions was conducted to document the long-term results of neurosurgical treatment of patients with severe brain lesions (Schalen, Nordstrom & Nordstrom, 1994). During 1981-84 310 patients were treated at the Department of Neurosurgery in Lund, Sweden. A total of 161 patients were treated after the introduction of a more aggressive management protocol in 1983. Out of this group 147 were classified as good recovery/moderate disability (GR/MD) 6 months after injury. The study attempted to answer two questions: 1) Do patients classified as (GR/MD) 6 months after severe head injuries return to a productive life and contribute to society?; and 2) Does a more aggressive treatment of patients with severe

head injuries increase the number of patients who contribute to society or does it increase the long-term costs to society?

Findings indicated that significantly more patients returned to work after the introduction of the aggressive management protocol 54% (n= 86), demonstrating the change in policy had a favorable outcome on the long-term effects on the economy (Schalen, et al., 1994).

Psychosocial Factors

Individuals utilize various coping mechanisms and demonstrate varying levels of ability to cope with neurological deficits associated with a traumatic brain injury. A study by Moore & Stambrook (1992) compared the coping strategies of individuals recovering from a traumatic brain injury or other neurological conditions. A pool of 88 individuals currently involved in a long-term quality of life outcomes were contacted by mail to inquire regarding interest in participating in this study examining coping abilities of TBI individuals. A total of 65 agreed to participate, however, this number was reduced to 53 due to missing data. All respondents were male with the median age of 38.3 years. Eighteen individuals were identified as having a severe closed head injury. Results indicated a considerable correlation between coping ability and the age of onset of the closed head injury. Age was also found to possibly play a greater role in later coping efforts and locus of control efforts (e.g., internal, powerful others, or chance). The younger individuals were at the time of brain injury, the more likely these individuals were involved with high-risk activities (e.g.

motorcycles, diving accidents, drunk driving, etc.) which may have predisposed them injury. In addition, individuals tend to remain in the chronological age they were at the time of injury, rather than their current chronological age, thus coping patterns are affected. Moore (et al., 1992) notes this study has limited generalizability due to the fact that the length of time post-injury and sampling limitations involved retrospective research, thus possibly creating sources of bias.

Miller (1993) identifies post-head injury trauma as similar to that of posttraumatic stress disorder (PTSD). Reactions are characterized by: various forms of anxiety, intrusive thoughts, preoccupation with the trauma, denial alternating with intrusive memories, feeling like a victim, feeling less attractive due to functional impairment and/or physical scarring, loss of social status, viewing the world as dangerous and bleak, depression, anger, hypoarousal of various somatic functions, sexual problems, inability to enjoy life, feelings of inadequacy, social withdrawal and behavior regression. Activity is reduced due to fear that specific locales will remind the individual of the accident.

Miller (1993) notes that there is considerable debate whether premorbid personality (pre-existing disturbance of self) determines the likelihood to experience psychosocial trauma. He feels people do respond to crisis on their own terms based on their own unique patterns of personality and cognitive style. Two approaches identified to be successful in treating patients with traumatic brain injury include the behavioral and psychodynamic approaches. The behavioral approach focuses on the desensitization to the stimuli that causes

severe reaction to the patient. The psychodynamic approach involves conceptualization and working through the various elements of transference in reconstructive psychotherapy.

Kaplan (1993) studied the psychosocial changes in individuals with severe traumatic brain injury and their significant others 1, 3, and 5 years after injury. Results showed a trend toward improvement in psychological and social functioning between the beginning and end of the study. Individuals showed an overall trend toward psychosocial improvement along with persistent mild to moderate emotional and social dysfunction. Approximately half of the 25 participants were rated as having minor problems with irritability, anxiety, indifference and initiation of behavior. These data show that individuals with severe brain injury seem to require about 5 years on the average to show significant psychosocial improvements, whereas physical capabilities often return more quickly.

Prigatano's (1990) study regarding individual's awareness of behavioral limitations after a brain injury, found that clients overestimated their behavioral competencies in comparison to their relative's reports. However, individuals with severe brain injury did not show greater memory or abstract reasoning difficulties than other traumatic brain injured individuals using standard neuropsychological tests. The author's inability to find a relationship between these measures has led him to believe that premorbid factors are important for alterations in mood and temperament.

Caregivers

A family's caregiving capacities are influenced strongly by: living arrangements, the availability of caregivers, competing responsibilities for caregiving, and the value systems and motivation of an individual family member, in addition to many other factors. These "factors" are difficult to assess. The ever changing family makes it difficult to evaluate family caregiving capacity. What are strengths in one family system may cause considerable distress for another. Members of the family get older, siblings move out, members make career decisions, parents sometimes divorce, retire and members die. Thus we must consider all these factors when considering the long-term care issues for an individual with traumatic brain injury or other debilitating illness (DeJong, Batavia, & Williams, 1990).

Research indicates that families do not abandon their own; care passes between generations throughout the life span. In today's society, families do not need to occupy the same dwelling to be involved with each other's well being. However, families do not seek outside assistance with caregiving tasks until the family has tapped their own resources (Burack-Weiss, 1995). Caregiving has been primarily identified as " women's work", although men were more likely to participate if the illness affects a spouse or mate if no other female is available.

Brooks & McKinlay (1983) conducted a study exploring families' views of personality and behavioral change after severe blunt head injury. Fifty-five

patients and their primary caregivers were studied 3, 6, and 12 months after injury. Individuals had been referred to the Regional Neurosurgical Unit of the Institute of Neurological Sciences in Glasgow, UK, for neurosurgical management following their head injury. Findings indicated that an increasing number of relatives described the patient showing a gradual personality change as the first year post-injury progressed. However, the pattern of change was identified by 3 months after injury, and persisted over the subsequent 9 month period. These perceived personality changes were in a negative direction, with reduced self reliance, sensitivity, and increased irritability being very apparent 3 months after injury (Brooks & McKinlay, 1983).

These findings are similar to those identified by Livingston, Brooks, & Bond (1985). Female caregivers of mild (control group) and severely brain injured males were interviewed three months after injury. The major complaint voiced by caregivers regarding the TBI individual was behavioral difficulties (lack of temper control and affective changes), with physical handicaps being a less frequent cause for complaint. The study also found a measurable psychiatric and social impact on the caregivers of severe head injured individuals 3 months after injury. The pattern of morbidity for individuals with severe brain injuries is one of mood disturbance together with social dysfunction in roles performed at home. Nearly half (45%) of the caregivers of the severely injured, score beyond the Leeds Anxiety threshold. It appeared that wives are more severely psychosocially handicapped in comparison to control wives than mothers compared to control mothers or wives. However, it should be noted that

depression was not a major problem in the sample presented (Livingston, et al., 1985).

In a 5 year outcome study of individuals with severe blunt head injuries, a close relative was interviewed following an initial study at 3, 6, and 12 months(Brooks, Campsie, Symington, Beattie, & McKinlay, 1986). The study attempted to chart the natural history of the objective and subjective burden consequences of severe head injury and to identify simple predictors of both types of burden. At 1 year, relatives reported high levels of behavioral, personality and cognitive change in the brain injured individual. Relatives reported suffering distress in relation to the family member's injury, and personality and behavioral changes. As the level of personality and behavioral increased, so did the level of the relative's distress.

The 5 year outcome found individuals with severe brain injuries maintaining at the same level identified at 1 year. However, in some cases individuals reported their life situation had deteriorated. Little improvement in patient outcome was noted, and in some cases, there was marked deterioration. For the relative the situation had deteriorated considerably. This was indicated by relatives reporting an increase in the subjective burden scores over 5 years and by increasing reports of negative and distressing changes in the brain injured individual as noted by the family. The more severe the initial injury, the more likely the relative report high levels of stress, as these individuals who were brain injured demonstrated increased incidence of negative behavior and personality change (Brooks, et al, 1986).

Problem solving abilities and coping strategies of individuals who experienced severe traumatic brain injury and their spouses were studied to ascertain adjustment for both parties (individual and spouse) during the first year of injury (Willer, Allen, Liss, & Zicht, 1991). As the authors note, much of the research on adjustment is focused on the injured individual, with little focus on family reaction and adjustment. The purpose of the study was to identify, through a structured small group discussion, current problems and coping strategies for both the brain injured individuals and spouses. Both brain injured men and women listed autonomy as the most significant problem they faced. Another major problem was fulfilling the role of spouse or parent. Both individual brain injured men and women had difficulty accepting unemployment, however, the men found alternative daytime activities that made them feel more productive. Women with brain injuries described becoming assertive as an important coping method, whereas men with brain injuries described gaining control of their aggressiveness as an important coping mechanism (Willer et al., 1991).

Able-bodied spouses also were found to differences in handling their changing roles, as well as their spouses who were brain injured . Able-bodied wives gave higher priority to loss of income as a problem, as the father is more likely to be the main source of income for the family. Able-bodied husbands also encouraged assertiveness and independence whereas the able-bodied wives allowed independence for their husbands. One further difference was noted in relation to the use of support groups. Both brain injured females and

able-bodied wives of brain injured males found the groups very helpful. Men in both groups agreed the groups were helpful for their wives but preferred other means of support for themselves, such as friends, family, physical activity, etc. (Willer et al., 1991).

The leading advocacy group for persons with traumatic brain injuries and their families or significant others is the National Head Injury Foundation (NHIF). Currently 31 state chapters are in existence and 375 support groups nationwide (Mann & Dittmar, 1992). The NHIF has approximately 300,000 members. Support for the NHIF comes form a variety of sources including individual bequests, membership dues, conferences, corporate donations and government grants.

Support groups can be very beneficial to brain injured individuals and their families or significant others to discuss issues such as return to work, community reintegration and moral support (Miller, 1992). It is important to have groups for survivors and a separate group for families and significant others. Each group has separate issues to talk through that would be inappropriate to discuss in a mixed group (Mann , et al., 1992).

IV. METHODOLOGY

Research Questions

The research questions are: 1) from a caregiver's perspective, how effective are behavioral services provided through the Traumatic Brain Injury Waiver Program in meeting behavioral needs?; and 2) What recommendations do primary caregivers have for the Traumatic Brain Injury Waiver Program? The research questions were addressed with both qualitative and quantitative questions. The purpose of the study is to explore information about TBI service effectiveness by directly gathering data from the primary caregiver to gain their perceptions of the Traumatic Brain Injury Waiver Program. For the purposes of this study, a primary caregiver was identified as the person primarily responsible for the care of a brain injured individual . This person could be served by a family member, friend, agency staff, guardian, or conservator.

Operational Definitions

Key variables and their operational definitions for this study are as follows:

TBI Waiver: A comprehensive program in Hennepin County for TBI individuals with severe behavior deficits which allows additional funding and training to meet client's needs who are at risk of nursing home or neurobehavioral hospitalization. Individuals are defined "at risk" by the Hennepin County's pre-admission screening team, who screen all individuals for the most cost effective means to provide for a client's comprehensive care needs in either a home or institutional setting.

Severe TBI: Refers to any individual who has a diagnosis of traumatic brain brain injury that is not degenerative or congenital, ranges in age from 18 to 65 years old, and is currently involved with Hennepin County's Traumatic Brain Injury Waiver Program (TBIW) (Minnesota Department of Human Services, 1995). For the purposes of this study only the identified primary caregivers of individuals who are receiving behavioral program services through the TBIW were asked to participate in the study.

Severe behavioral problems: "are those behaviors that interfere with the client's ability to live in the community; the individual requires intense levels of behavior modification and supervision. They are usually manifested in Level 1 behaviors which include: Self-Injurious Behavior, Physical Injury to Others, Destruction of Property" (Minnesota Department of Human Services, et al, 1995, p.6). The Level 1 behaviors are measured by recording the frequency and duration of behavioral problems. A rating scale for frequency of behavior ranges from 0 (absent) to 5 (hourly). For duration the scale ranges from 1 (thirty seconds or less to redirect a client) to 5 (more than 10 minutes to redirect a client).

Case management services: A comprehensive plan to meet a brain injured individual's unique care needs provided by a licensed social worker or RN to individuals through Hennepin County's Community-Based Long-Term Care Division. The purpose of the TBIW Program is to assist in coordinating a comprehensive plan to address health, vocational, behavioral and recreational needs to enhance an individual's potential for

success. Individual and family input are incorporated into the service plan.

Primary caregivers: This term refers to the individual who is the primary person responsible for the care of another. For the purpose of this study, the primary caregiver will be identified by the county case manager as the person who is primarily responsible for the care of an individual with TBI. This individual could be an agency employee, family member, friend, guardian or conservator.

Behavioral programming: Consists of individually designed strategies to decrease the client's severe maladaptive behaviors which have interfered with the client's ability to remain in the community. Program components include: a complete assessment of the maladaptive behavior(s), development of a structural behavioral intervention plan, implementation of the plan, on-going training and supervision of caregivers and behavioral aides, and periodic reassessment of the plan.

Procedure for Protection of Research Participant

This study began with the approval of Augsburg College's Institutional Review Board and Hennepin County Community-Based Long-Term Care Division (Appendix E). Through the cover letter, potential research participants were informed of the purpose of the study, identity of the principal researcher, and how individuals were selected for participation. Any possible risks, benefits, or expectations of participants were also identified (Appendix F).

A statement addressing the confidentiality of data shared with the researcher was also incorporated into the cover letter. Participants were informed that they had the right to decline participation in the study or may discontinue their involvement in this study at any time without fear of reprisal from Augsburg College or Hennepin County.

Measurement Tool Design

The measurement tool used for this exploratory study was a combination of open-ended and closed-ended questions presented in a 22 question self-administered questionnaire. The questionnaire included four questions on background information on the individual client receiving behavioral programming services through the TBIW Program. Five questions focused on issues regarding the primary caregiver. Questions in this area identified the caregiver's relationship with the brain injured individual and attempted to see how relationships with family members may have changed since the traumatic brain injury. The remaining twelve qualitative questions focused specifically on behavioral programming. Caregivers were asked to retrospectively review how the nature of the individual's level of behavior(s) prior to becoming involved with the behavior programs offered through the Traumatic Brain Injury Waiver and comment what effect, if any, the program had on these behaviors. Specific areas targeted were: social relationships, housing, access to health care, access to the community (e.g., shopping, recreational activities, etc.), and

obtaining and maintaining employment. Caregivers were also provided with the opportunity to provide recommendations for future programming services.

Data Collection Procedure

This study began with the approval of Augsburg College's Institutional Review Board and Hennepin County Community-Based Long-Term Care Division. Through the cover letter potential research participants were informed of the purpose of the study, identity of the principal researcher, and how individuals were selected for participation. Any possible risks, benefits or expectations of participants were also identified (Appendix F). Research participants received, by mail, an envelope containing the cover letter, the research questionnaire (Appendix G) and one self-addressed stamped envelope for the return envelope. Individuals also found an enclosed self-addressed stamped postcard from Hennepin County Community-Based Long-Term Care Division, for individuals who may have had questions regarding the Waiver Program and wished to speak to their client's case manager. The first letter and accompanying questionnaire was sent February 24, 1996. Related to feedback from one potential caregiver , the second cover letter was modified to address individuals who may be the primary caregiver for more than one individual. A second mailing was sent two weeks later on March 9, 1996 (Appendix H). Potential participants were informed through the cover letter that their involvement with the research study would end upon mailing the

questionnaire. Completion and return of the questionnaire implied consent to participate.

Data Analysis

Results presented are based upon responses to qualitative and quantitative questions presented in a self-administered questionnaire sent to twenty-one identified primary caregivers. Five responses were received through the first mailing. An additional two questionnaires were received from the second mailing.

As the purpose of the study was exploratory, the researcher made note of all issues raised related to the research questions presented. Averages and modes were calculated where multiple responses by participants were similar. Although the response rate was low, a great deal of valuable information was received from the seven respondents.

V. FINDINGS

Description of Respondents

Twenty-one subjects were identified as receiving behavioral programming through Hennepin County's Traumatic Brain Injury Waiver Program. Primary caregivers of these individuals were sent a cover letter and a Behavioral Services Questionnaire explaining the purpose of the research and requesting participation in the study. Five responses were received through the first mailing. The second mailing, two weeks after the initial mailing, resulted in an additional 2 responses. Although the response rate was low (33%), the respondents comprised an array of individuals. The 7 responding caregivers included the following categories: family member, conservator of person and finance, and professional caregivers (agency staff). Caregivers were asked to retrospectively review how individual's with brain injuries behaviors were prior to becoming involved with the behavior programs offered through Hennepin County's Traumatic Brain Injury Waiver Program and to comment on what effect, if any, the program had on these behaviors.

Background Information

The first section of the behavioral services questionnaire focused on the background information of the clients being served. Of the 7 clients identified, 5 were males and 2 were female. The majority of clients (n= 5) were in the age range 36 to 45 years. One person was in the 26 to 35 range and 1 person in the

56 to 65 category. Both females had sustained their head injury related to a motor vehicle accident. Males sustained their injury via motorcycle accident (n= 3) or stroke(n= 2). With regard to marital status 4 were single (3 male, 1 female) . One individual was married but was not currently living with his/her spouse, and 2 were divorced.

Primary Caregiver Information

Caregivers were asked to comment on the client's current living arrangements and if their living arrangements have changes since the brain injured individual was enrolled in the TBIW. the majority of caregivers (n= 5) stated the living arrangements had changed since enrollment in the Traumatic Brain Injury Waiver Program. One caregiver comments, " Was living in foster home but the foster parent died. Currently lives at a group home . " Another responded: " He has become more outgoing. Taking better care of himself (personal hygiene, etc.), cooking, washing clothes and assisting others." Family caregivers were the most accurate indicator of defining change(s) for individual brain injured individual . A group setting was noted as the current living arrangement for most persons (n= 5).

Caregivers were asked to describe the brain injured individual's current relationship with his family. When commenting on the relationship with family one caregiver states, " Father is dead. Mother lives in Twin Cities and gets together with client weekly. Client has a child that lives with the client's spouse. Client sees her weekly, usually with another family member ". Other responses

include: " good relationship, limited contact ", and " Loves to go home but has an elderly parent and all the client does is lay around. The parent does not cook for him..... not a good situation ".

In relation to family relationships, caregivers were asked to comment if changes in the relationship had resulted because of the person's brain injury. Two respondents stated the relationship had not changed. Professional service provider staff had difficulty responding to this question related to limited knowledge of the brain injured individual's history. Family caregivers noted a change in the individual's response to other family members: " more caring about relatives. Wants to be a real part of the family. " Other family commented the role of the individual who was brain injured had changed, as they were not seen in the same light by other family members.

Caregivers were asked to comment on what new means of support were now available to them through the Traumatic Brain Injury Waiver Program. No new means of support for caregivers were identified, however several caregivers (n= 3)identified new support systems for the individual who was brain injured.

Behavioral Services

Caregivers were asked to comment on whether the individual had any behavioral services prior to his/her involvement in the Traumatic Brain Injury Waiver Program. Particular services included mental health/counseling, chemical health intervention and other services for behavior issues. Five

caregivers responded to this question. Three brain injured individuals (both females) had received mental health/counseling, 1 had chemical health intervention, and 2 individuals had received other services either from a local metropolitan rehabilitation center that provides physical and emotional support to individuals with congenital or acquired disabilities or behavior management by means of counseling and medication. Professional service providers again had difficulty commenting on the individual brain injured person's past history, as often he/she was not caring for the individual prior to the initiation of the TBI Waiver.

Caregivers were asked to identify what services, if any, the brain injured individual was currently receiving through the Traumatic Brain Injury Waiver. Of the 7 caregivers, 3 identified the individual as receiving service(s). The most common support noted was therapeutic counseling with a pscyologist (n= 3). One of these individuals was also involved with group meetings for additional support. The other caregivers either did not know what services were being provided (n= 2) or stated the individual was not currently receiving services (n= 1).

Caregivers who had identified the brain injured person as receiving behavioral services(n= 3) were questioned whether they had observed any changes in behavior since the services were initiated through the Traumatic Brain Injury Waiver Program. Responses to this questioned varied. One caregiver stated: " A little better but he is a very hard person, he doesn't want to get better ". Another states, " Better communication, less behavior outbursts

on home visits ". Individuals who answered they were unsure if services were in place also chose to answer this question (n= 2).

Caregivers (n = 5) were questioned about whether the brain injured individual had a behavior plan. Of these respondents, only 1 stated awareness of a behavior plan. Two were uncertain if one existed, and 2 stated they were not aware of a behavioral plan. However, the caregiver who stated awareness of the behavioral plan stated it was being followed by all service providers and caregivers.

The final area of behavior services addressed what effect, if any, an individual's behavior had on the following areas: social relationships, housing, access to health care, access to the community (e.g., shopping, recreational activities, etc.), and obtaining and maintaining employment. In relation to social relationships respondents (n= 3) stated identified behaviors created a barrier. One caregiver stated, " Vulnerable, naive..... lacking on social skills ". Another responded " Has a hard time interacting with people. Wants to meet a woman. Has a hard time in speaking. Difficult in emotions but working on it ".

Housing was noted as a significant barrier for one individual. The caregiver stated that the brain injured individual he/she worked with has experienced difficulty in this area, " Before he never took care of his living quarters- kept everything and anything(junk). He hid things because he said it was " collector " items. He is slowly learning " house " cleaning procedures. It's constant in learning and teaching ".

With access to health care, a caregiver stated the individual brain injured person had experienced difficulty finding care, but currently has his needs met. Respondents noted , several identified barriers in relation to getting out in the community (n = 3). One caregiver stated, " Loves to shop. Spends money on things he doesn't need. Traumatic Brain Injury Waiver Program is working with him on it and a budget ".

In regards to employment, caregivers (n= 3) identified client's behavior as a barrier to employment. One caregiver commented on the brain injured person's current employment:

" He's working. First time in years. They make ' piece work pay' . Because their slow they make very little. They get frustrated with themselves because they work slow and make little money. We try to say that they must be patient as they been out of the workforce for awhile, that with time things will improve ".

One respondent stated behavior did not create barriers of employment as the individual was " too badly brain damaged to work ". Two respondents stated that behavior problems (impulsive behavior and lack of control over their emotions) creating barriers in retaining employment, once a position was obtained.

Respondents who identified barriers were then asked to identify how barriers may have changed as a result if the behavior services provided through the Traumatic Brain Injury Waiver Program. Respondents (n= 3) stated a positive

effect in relation to involvement with the Waiver Program. One caregiver stated:

" Barriers have changed in all areas. He has improved because of the Traumatic Brain injury Waiver Program. He still have a way to go, but most definitely has made improvements with the Traumatic Brain Injury Waiver. Too bad the Waiver Program wasn't around a few years ago. "

Effectiveness of the Traumatic Brain Injury Waiver Program

The final area of the questionnaire focused on examining, from the caregiver's perspective, in what ways the Traumatic Injury Waiver Program was helpful to the brain injured individual. Several caregivers commented on the new opportunities made available by the Waiver Program: " It's providing a residential setting that promotes independence with supports; funding a structured work program that promotes growth and assists in developing skills necessary for returning to work and/or living more independently ".

Other comments include the following:

" He needs constant help and guidance and the Waiver Program works very good with him ".

" She's being treated for relevant issues rather than as a mentally retarded or mentally ill person ".

" Made it possible to be moved from a hospital to a group home ".

" Learning to become more self sufficient. Teaching him daily living, helping him with his confidence, which he has gained within himself. Had a very low self

esteem- is greatly improved. He's on medication which helps his mood swings and anger. They talk together, go out on activities in the community. Healthy things. He needs support. I can't see him ever living totally on his own ".

Areas deemed as least helpful were also discussed. Of the responses to this question (n= 2), clarification of eligibility requirements for the program and differences in level of services provided between individuals with brain injuries were mentioned.

Caregivers were also requested to make recommendations for future programming. One respondent noted, " It would be nice to see an expansion in the services able to be funded by the Waiver to include vocational services of some sort ". Another commented: " He would like to have someone bring him shopping as opposed to having someone do it for him " . A final comment noted by one caregiver expressed the sentiment of the majority of caregivers who responded to the questionnaire:

" I feel without the Traumatic Brain Injury Waiver Program, there would be many people forced to live in a more controlled living environment such as nursing homes. The progress I've seen in people's lives who are on the Waiver is incredible ".

VI. DISCUSSION & IMPLICATIONS

Comparison of Findings to Literature Review

Findings in this study appear to be consistent with issues raised in the literature regarding the severely brain injured individual, caregiver, and/or family relationships. Discussion will focus on the results of mailed self-administered questionnaires received from identified primary caregivers. Specific areas to be addressed include background information on the brain injured individuals, identified primary caregivers, psychological aspects of injury, community integration, and vocational opportunities for brain injured individuals.

Background Information on Severely Brain Injured Individuals

As research has indicated, two-thirds of those affected with traumatic brain injuries are males between 15 and 24 years old with life expectancies of an additional 35 to 50 years (Minnesota Department of Human Services, 1990). Trauma has been identified as the leading cause of death for all individuals under the age of 35 years, with head injuries accounting for approximately 65% of annual trauma injuries (MacKay, et al., 1992). Of the subjects identified in the study, 5 of 7 were male. Data were not collected about the age of injury onset on any of the subjects, but 2 caregivers provided information that indicated 2 brain injured individuals (a male and female) were in their early twenties when their injury occurred and currently range from 35 to 46 year of age .

Caregivers

Research indicates families do not abandon their family members; care passes between generations throughout the life span. Outside assistance is sought only after the family has tapped their own resources (Burack-Weiss, 1995). According to results of the study, 4 of 7 respondents were family members. Burack-Weiss further note caregiving responsibilities are primarily identified as "women's work", however, men were more likely to participate if the illness affects a spouse or mate if no other female is available. One participant was identified as married in the study, but was not residing with his/her spouse.

Several studies (Brooks & McKinlay, 1983; Livingston, Brooks, & Bond, 1985; Willer, Allen, Liss, & Zicht, 1991; Brooks, Campise, Symington, Beattie, & McKinlay, 1986), have explored family member's perception of personality and behavioral changes in individuals with severely brain injury . All studies commented the major complaint voiced by caregivers was not the degree of physical handicap, but the level of behavioral difficulties (lack of temper control and affective changes). In contrast to these studies, of the respondents (n= 7) 2 noted no change in relationship with the family related to behavior. The professional care staff were unaware of client's relationship with their families prior to the their injury. One respondent stated the relationship between the client who was brain injured and his/her family improved after their accident. The respondent stated "He's much more interested in his family. Wants to be a 'real' part of the family. Had little involvement with us before (the accident)". Two respondents reflected the view presented in the literature,

commenting on the brain injured individual's mood swings and lack of responsiveness to other family members.

Research on brain injury support groups has found that it is parents, rather than spouses who tended to continue their participation in the support group for extended periods of time (Miller, 1992). The author states the reasons are twofold: Spouses may be less well prepared than parents to adjust to and accept a potential caregiving role for the injured individual and issues of major importance to spouses do not lend themselves to be aired in a group forum.

People are affected by brain injury in many facets, including physical, neuropsychological, emotional, and social impairments (Klonoff, et al., 1993). The most difficult task is aiding individuals and their families or significant other(s) on setting realistic goals for the future. Klonoff's and associates state family education is essential in the rehabilitation process. They further recommend mandating attendance at a local support group, in addition to meeting one on one with a psychotherapist or other counseling entity to discuss matters that are not appropriate to discuss in the group setting. Support groups can be very beneficial to families to discuss important issues such as returning to work, community reintegration and moral support (Miller. 1992).

The leading advocacy group for persons with traumatic brain injuries and their families or significant other(s) is the National Head Injury Foundation (NHIF). Currently 31 state chapters are in existence and 375 support groups nationwide (Mann & Dittmar, 1992). The NHIF has approximately 300,000 members. The foundation serves to educate consumers as well as professionals on issues that

face brain injured individuals. Of the 7 respondents, none commented on attending a group or receiving other means of support for themselves at this time.

Psychological Aspects to Traumatic Brain Injury

Research indicates individuals utilize various coping mechanisms and demonstrate varying levels of coping ability to cope with neurological deficits associated with a traumatic brain injury (Moore & Stambrook, 1992). The authors conducted a study comparing individuals recovering from traumatic brain injuries to individuals with other neurological conditions in a long-term quality of life outcome. Findings indicated a correlation between coping ability and the age of onset of the closed head injury. Age was found to possibly play a greater role in later coping efforts and locus of control efforts (e.g., internal, power of others, or chance). Little data were received from the 7 respondents about these aspects since they were not addressed directly in the questionnaire. However, 2 individuals (a male and female) were identified to be in their early twenties when their injuries occurred.

Miller (1993) identified post-head injury trauma as similar to that of posttraumatic stress disorder (PTSD). Of the 7 respondents in the study, 2 described the brain injured individuals as angry, socially withdrawn, expressing feelings of inadequacy, and demonstrating increased anxiety and depression. Priganto's (1990) study regarding brain injured individual's awareness of behavioral limitations after a traumatic brain injury found clients overestimated

their behavioral competencies in comparison to relatives' reports. Respondents in this study indicated individuals overestimated their true abilities the majority of the time (n= 5). Miller notes there is considerable debate whether premorbid personality (pre-existing disturbance of self) determines the likelihood to experience psychosocial trauma.

Kaplan (1993) studied psychosocial changes in individuals with severe traumatic brain injury and their significant others 1, 3, and 5 years post injury. Individuals were shown to have an overall trend toward psychosocial improvement, along with persistent mild to moderate emotional and social dysfunction. Four of 7 respondents noted improved socialization skills, with remaining impairment in control of emotions and impulse.

Community Integration and Severe Brain Injury

Shue's (1993) research indicates that there is limited research available about program options available in the community for individuals with significant cognitive impairment in addition to severe behavior difficulties. Shue's Repartriation Community Program pilot project in Ontario, Canada, attempted to provide community-based services as well as create a service delivery system and interagency collaboration that could be implemented in other providences. This same approach has been orchestrated by Hennepin County's Community-Based Long-Term Care Division by attempting to provide comprehensive services in a community-based setting (Minnesota Department of Human Services, 1992).

An alternative model of community integration was developed by Willer & Corrigan (1994), the Whatever It Takes Model (WIT). This model focuses on the self-determination and desire for individuals with severe traumatic brain injuries to have the ability to make informed choices . The model encourages individuals to participate to the maximum of their ability, but also recognizes the fact that cognitive and behavioral deficits will interfere with sound decision making, therefore, options will need to be tailored to the individual's abilities. The Traumatic Brain Injury Waiver Program, developed in Minnesota to assist traumatic brain injured individuals, is based on the medical model. Thus decisions for the individuals are made by professionals (doctors, case managers, psychologists, etc.). Individuals and their families are brought into this "loop" when these professionals deem it is appropriate (S. Bulger, personal communication, October 8, 1995).

Few service models address long-term community living for individuals with severe brain injury (Harrick, Krefting, Johnston, Carlson, & Minnes, 1994). The Transitional Living Center of Kingston, Ontario (KLTC) was identified as a community-based post-acute rehabilitation program, which provided both residential and day treatment programs, in addition to providing support and education for family members or significant others. Average length of stay was 6 months. Functional outcomes on a long term basis (1, and 3 years post discharge) of 21 individuals found improvements after one year and either remained stable or improved at the 3 year follow-up. No indication was noted by Hennepin County Community-Based Long-Term Care that anyone receiving

services through the Traumatic Brain Injury Waiver Program has improved to the degree noted in this study (C. Larson, personal communication, November 12, 1995). In relation to responses from caregivers, all study respondents (n= 7) found positive behavioral changes in the brain injured individual since enrollment in the Traumatic Brain Injury Waiver Program.

The idea of case management has been a constant theme with the traumatically brain injured population (Austin, 1990). Amado, McAnally & Linz (1989) also note the importance of defining the client population served in relation to the existing system. Hennepin County's Community-Based Long-Term Care Division (Minnesota Department of Human Services, 1995), in conjunction with the Department of Human Service's Task Force (Minnesota Department of Human Services, 1994) are working collaboratively to modify services to best serve individuals with traumatic brain injury statewide. Austin (1993) notes the community-based long-term care programs enable disabled individuals to remain in a community setting by providing needed services. The overall goal is to increase the knowledge base of the individual brain injured person and their support system to enable them to have more control over their lives (Roach, 1993; Hennepin County Community Health Department, 1993).

Vocational Options for Individuals with Severe Brain Injury

Courtney (1994) has addressed the funding issues that currently face the state of Minnesota in expanding vocational programs for traumatic brain injured individuals. However some mode of employment needs to encompass

vocational needs. Several respondents commented on the need for more vocational opportunities. One caregiver noted that it would be helpful to have vocational services for all who are interested in working. Currently only those who are cognitively able and have "controllable" behavior(s) are offered work (C. Larson, personal communication, November 12, 1995). Lubusko et al., (1994) commented how society places high value on people who are productive and actively contribute to society. Caregiver's in the study noted that brain injured individuals who were working were frustrated by their meager income and job assignments. Wedell et al., (1980) found that of 44 young adults with severe brain injury only 5 individuals were able to return to their former jobs. Twenty individuals were unable to work at all.

Currently there are no individuals with severe brain injury employed in any capacity through the Waiver Program. Opportunity Workshop provides all sheltered work programs for individuals who receive behavioral program services through the Traumatic Brain Injury Waiver Program (J, Hartman, personal communication, January 13, 1996). The program is designed to provide a comprehensive structured day program for individuals with severe brain injuries, based on specific client's needs. The goal is to prepare the individual for the work environment and address behavioral problems that inhibit the individual brain injured person's ability to work effectively.

Study Limitations

Although the findings of this study are valuable, it cannot be assumed that all caregivers would evaluate services offered through Hennepin County's Traumatic Brain Injury Waiver Program in the manner as study participants. Therefore with the limited number of respondents and lack of random selection, it is not possible to generalize results of the study to the entire population who currently receive behavioral services. Reactions of individuals with the traumatic brain injury were not incorporated into the design of the study. Their input may have been helpful to gain a broader perspective on program effectiveness. With limited data about who identified primary caregiver's were, it was difficult to make a correlation between literature reviewed and reality.

Implications for Practice

In light of the findings, the implications for practice include: improved vocational program to address the needs of all individuals who receive behavioral programming services, improved communication from case management staff to keep caregivers aware of current behavior programs, and inclusion of the brain injured individual to allow him/her to participate to the fullest of his/her ability.

Case managers need to actively working with caregivers to assure they fully understand the current treatment and behavioral plan for the individual brain injured person. One can not assume because the caregiver possesses a copy of the plan that he/she comprehend its contents. Periodic review of this

information with the client and their caregiver is essential for effective behavioral management and for all parties to identify strengths and weaknesses of a given client. The fact that only one caregiver knew a behavior plan existed strongly suggests a need for clearer communication between case managers and the identified caregiver.

In relation to the models of rehabilitation/ community integration, the TBIW Program attempts to expand the medical model to encompass other aspects people with severe brain injury experience, including social, vocational and emotional dimensions. As the program continues it would be beneficial to periodically re-evaluate the program with direct input from the individual clients and their caregivers to assure the program is meeting the current needs of clients.

Recommendations for Future Research

Due to the poor response rate of this study, it would be beneficial to replicate this study at a future date and time. When this study is redone, three aspects should be incorporated into the study. First, individuals with severe brain injury should be involved in this process. This would be best accomplished by interviewing these individuals. Secondly, more information should be gathered on who the caregivers are. For instance determining the age and sex of the identified caregiver may assist Hennepin County and researchers in addressing the needs of the identified caregivers. This would be helpful in gaining a better perspective of what needs caregivers may have. More

information should also be gathered on sheltered or other forms of employment currently available to these individuals. It appeared caregivers had little idea of exactly what vocational opportunities were available to individuals with brain injuries.

Finally, it would be helpful to ascertain the age and circumstances how the individual sustained his/her traumatic brain injury. This information could assist professionals in determining what populations and age groups should be targeted for various prevention programs to educate young adults identified at risk for sustaining a traumatic brain injury.

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1) Due to its size, metropolitan Minnesota, was divided into two regions. Dakota, Ramsey, Scott, and Washington Counties comprise one region. Hennepin County, the largest county in terms of population density in the state, comprises the other. 2) Northwestern Minnesota includes the counties of Becker, Beltrami, Clay, Clearwater, Hubbard, Kittson, Mahnomen, Marshall, Norman, Otter Tail, Pennington, Polk, Red Lake, Roseau, Traverse, Wadena, and Wilkin. 3) Central Minnesota is comprised of the following counties: Anoka, Benton, Carver, Chisago, Crow Wing, Douglas, Grant, Isanti, Kanabec, Mc Leod, Meeker, Mille Lacs, Morrison, Pine, Pope, Sherburne, Stearns, Stevens, Todd, and Wright. 4) Northeastern Minnesota is comprised of Aitkin, Carlton, Cass, Cook, Itasca, Koochiching, Lake, Lake of the Woods, and St. Louis. 5) Southeastern Minnesota includes: Blue Earth, Dodge, Fairbault, Fillmore, Freeborn, Goodhue, Houston, Le Seuer, Martin, Mower, Nicollet, Olmsted, Rice, Sibley, Steele, Wabasha, Waseca, Watonwan, and Winona Counties. 6) Southwestern Minnesota includes Big Stone, Brown, Chippewa, Cottonwood, Jackson, Kandiyohi, Lincoln, Lyon, Murray, Lac Qui Parle, Nobles, Pipestone, Redwood, Renville, Rock, Swift, and Yellow Medicine Counties. State Regional Treatment Centers currently served include: Ah-Gwah-Ching, Anoka, Brainerd, Cambridge, Fairbault, Fergus Falls, Moose Lake, St. Peter, and Willmar (Minnesota Department of Human Services, 1995).

1. Case management - All clients receiving Traumatic Brain Injury Waiver services are required to have an assigned case manager when their care plan is developed. The case manager is responsible for: assisting the client in gaining access to medical assistance, as well as medical, social, educational, or other needed services, regardless of funding source; monitoring services to optimize client's health and safety; reassessment of client's condition when case mix classification change is warranted, or at least every six months. (This rate determines how much the county pays for services. The higher the case mix, the greater the cost. Case mix ranges from level "A"(lowest) to level "K"(highest)).

   Case managers must meet the qualifications of either a social worker or registered nurse. Social workers must possess an accredited four-year college degree with a major in social work or closely related field and pass a written examination covering knowledge of counseling, interviewing, and social science principles. Registered nurses must be currently licensed in Minnesota and have a knowledge of community resources for persons with disabilities.

2. Adult day care - Services may be provided to the client two or more hours per day, one or more days per week on a regularly scheduled basis. Services should encompass the health and social service needs required for the client's optimal functioning level . Physical, occupational and speech therapy may be provided in addition to day care.

3. Behavioral programming - Consists of individually designed strategies to decrease the client's severe maladaptive behaviors which have interfered with the client's ability to remain in the community. Behavior programming includes: an assessment of the maladaptive behavior(s), development of a structured behavioral intervention plan, implementation of the plan, on-going training and supervision to caregivers and behavioral aides, and periodic reassessment of the plan.

   A. Behavioral analyst - A behavioral analyst is responsible for the following services:
   a) designing and overseeing the implementation of behavioral programming in coordination with the psychologist or clinical social worker; b) providing ongoing analysis in interpretation of the behavioral program data; c) on-call consultation with other individuals involved with the client; d) participating in progress review meetings; and e) coordinating with the psychologist or clinical social worker, the scheduling, training, and supervision of behavioral staff.

A behavioral analyst must have a baccalaureate degree in a social services discipline and three years of experience working with clients with behavioral deficits. Two years of experience as a behavior analyst may substitute for the above education requirement.

B. Behavioral specialist - A behavioral specialist is responsible for the comprehensive knowledge regarding the client's behavioral plan to provide ongoing support for direct care staff in executing the behavior plan. This individual is most often associated with the client's residential or day program as an "in-house" expert.

A behavioral specialist must have an Associate's degree in a social service discipline, two years of experience working with clients with behavior deficits, and a determination by the psychologist, clinical social worker, or behavioral analyst that the individual has the skills required to provide behavior modification intervention to the client.

C. Behavioral aide - A behavioral aide is a member of the direct care staff who is responsible for the day to day administration of the behavioral plan. A behavioral aide is usually employed by the client's residential or day program.

A behavioral aide must have a minimum of 4 hours of training in understanding the cognitive and behavioral effects of brain injury; 20 hours of instruction in behavior modification techniques; and a determination by the psychologist, clinical social worker, or behavioral analyst that the individual has the skills required to provide behavior modification intervention to the recipient.

4. Chore services - Chore services are needed to maintain the home in a clean, sanitary and safe environment. This includes heavy household chores such as washing floors, windows and walls, tacking loose rugs and tiles, moving heavy items of furniture in order to provide safe access inside the home, and shoveling snow to provide safe access to client's home. These services are provided under the Traumatic Brain Injury Waiver only in cases where neither the client nor anyone else in the household is capable of performing or financially providing them and no other sources of funding are available.

5. Cognitive rehabilitation therapy - This therapy is specifically designed to improve cognitive functions such as attention, concentration, information processing skills, learning, memory, planning, problem solving, executive functions (processes by which a person plans,

prioritizes, organizes, sets goals, executes strategies, and monitors his or her behavior), self-control, and visual-spatial deficits. Cognitive therapy is provided to an individual as an outpatient or in the community as specified in the client's plan of care.

Services are provided by licensed psychologists or by individuals with a baccalaureate degree in one of the behavioral sciences and are under the supervision of a licensed psychologist. Services may also be provided by occupational therapists or speech-language pathologists.

6. Companion services - This service consists of non-medical care, supervision and socialization that is provided to a functionally impaired adult. A companion may assist a client with such tasks as meal preparation, laundry, and shopping, but does not perform these activities as discrete services. A companion may also perform light housekeeping tasks which are incidental to the care and supervision of the client or accompany the individual in the community. Companion services are provided in accordance with a therapeutic goal as identified in an individual's plan of care.

   Companions have no formal training but must have had experience and/or training in homemaking skills, and/or caring for individuals with disabilities or brain injuries. He/she must have the ability to read, write and follow written instructions. He/she must also be able to converse effectively on the telephone, work under intermittent supervision, and manage any emergency situation that may arise. This individual can not be the client's legal guardian or be related to the client.

7. Extended home health services - These services include care by home health aides, registered nurses, licensed practical nurses, and therapists (including respiratory therapists). All home health nurse and aide visits included in the Individual Service Plan (ISP) require prior authorization from the case manager.

8. Extended psychological testing /Extended explanation of findings - Psychological testing is the use of other psychological tests or other psychometric instruments that determine the status of the client's mental, intellectual, and emotional functioning.

   Explanation of findings is the explanation of a diagnostic assessment, psychological test results, treatment program, or other accumulated data and recommendations to the client's family, primary caregiver, or other responsible persons.

   Providers for these services include the following state licensed mental health professionals: psychiatrists, psychologists, clinical social workers,

psychiatric or mental health nurses, and marriage family therapists who are currently employed by a community mental health center.

9. Extended personal care - Personal care services include assistance with eating, bathing, dressing, personal hygiene, and activities of daily living. This service may also include meal preparation and such housekeeping chores as bedmaking, dusting, and vacuuming, which are essential to the client's health and welfare. An individual who receives such services does not have to be capable of directing his or her own care. Care direction may be provided by a family member not residing with the recipient, or by a significant caregiver, who is not a PCA (personal care assistant)), or by the case manager. A personal care assistant may also accompany the client into the community.

   A personal care assistant has received training in one or more of the following areas:

   A. A nursing assistant program or its equivalent and is currently licensed by the state of Minnesota.

   B. A homemaker/home health aide pre-service training using curriculum recommended by the Minnesota Department of health.

   C. An accredited educational program for registered nurses or licensed practical nurses.

   D. A training program that provides the assistant with skills required to perform personal care assistant services.

   E. A determination by the supervising RN that the assistant has the skills required through training and experience, to perform personal care services.

      Relatives may provide personal care assistant services if they meet one of the qualifications for financial hardship criteria. These services in the Individual Service Plan must receive prior authorization by the case manager.

10. Extended supplies and equipment - This includes devices, controls, or appliances which enable a client to increase his/her ability to perform activities of daily living, or perceive, control, or communicate with the environment in which he or she lives. This also includes items necessary for life support, ancillary supplies necessary for proper functioning of such items, and durable and non-durable medical equipment not available under Medical Assistance.

11. Family counseling and training - Family counseling and training includes services for the client as well as the family with whom he/she lives or routinely provides care. Family is defined to be the person(s) who live with or provide care to a client and may include a spouse, children, friends, relatives, foster family, or in-laws. Family does not include individuals who are employed to care for the client.
Training is for the purpose of increasing the client's or family member's capabilities to maintain and care for the client in the community. It includes use of equipment and treatment regimes as specified in the care plan. Periodic training updates may be necessary to safely maintain the client in the community. All individuals or vendors who provide training services must be Medicare certified and/or enrolled as a Medical Assistance provider.

    Counseling may include helping the client and/or his or her family members with crisis, coping strategies, stress reduction , etc. For qualifications to perform counseling duties, please refer back to provider standards listed with Extended psychological testing/Explanation of findings.

12. Foster care - Adult foster care is available to clients 18 years of age and older. Adult foster care is defined as a licensed, adult-appropriate, sheltered living arrangement for up to four functionally impaired adults in a family-like environment. Adult foster homes provide food, lodging, protection, supervision, and household services. They also provide living skills assistance or training, medications assistance, and assistance with managing finances. The case manager visits the client at least every six months and may also be involved in the development and review of the individual resident placement agreement.

13. Homemaker services - Homemaker services include meal preparation, routine household care, shopping and errands, assisting with daily activities, arranging transportation, providing emotional support and social stimulation, and monitoring safety and well being.

14. Home modifications and adaptations - This includes physical adaptations to the home which are necessary to ensure the health, welfare and safety of the individual, or which enable the client to function with greater independence in the home. Such adaptations may include installation of ramps and grab-bars, widening of doorways, modifications of bathrooms, central air conditioning, carpeting, etc..

15. Independent living skills and therapies - Independent living skills (ILS) services are directed at the development and maintenance of community living skills and community integration. Services may include

supervision, training, or assistance to the client with self-care, communication skills, socialization, sensory/motor development, reduction/elimination of maladaptive behavior, community living and mobility.

Individual living skills therapies under the Traumatic Brain Injury Waiver include therapeutic recreation, music therapy, and art therapy. These may be provided to the client on an individual basis or in a group.

16. Respite care - Respite care services may be provided on a short-term basis because of the absence or need for relief of those persons normally providing care. Respite care under the Traumatic Brain Injury Waiver is limited to 30 consecutive days with a total of 90 days available during the year. Respite care may be provided in either an out-of-home setting or in the client's own home.

17. Structured day program - Structured day program (SDP) services are directed at the development and maintenance of community living skills. The services take place in a non-residential setting separate from the home in which the recipient lives. Services will normally be furnished 2 or more hours per day, for 1 or more days per week, on a regularly scheduled basis.

    Services include supervision and specific training to allow the recipient to attain his/her maximum potential. SDP services may include social skills training, sensor/motor development, and reduction/elimination of maladaptive behavior. Services aim to prepare the individual for community reintegration (teaching concepts such as compliance, attending, task completion, problem solving, safety, money management, etc.) are also included. Physical, occupational , speech and cognitive rehabilitation therapy are provided as needed to recipients.

    The purpose of the program is to serve two types of clients: those who will benefit from continued rehabilitation and those who need a very structured environment due to severe behavior problems which prevent them from participating in adult day care or other day programs.

    The SDP does not include supportive employment services or any other services funded through the Division of Rehabilitation Services (DRS).

18. Extended transportation - Transportation service is offered to enable clients to gain access to waiver and other community services as specified in their individual care plan. All other means of transport (family, friends, neighbors, and community agencies) should be exhausted prior to utilizing this service due to the cost (as cited in

Minnesota Department of Human services, 1992. DHS Publication No. #95-57A, Attachment C, pp. 1- 18).

TBI WAIVER APPLICATION SUPPLEMENT FOR NURSING FACILITY (NF) LEVEL APPLICANTS

To be eligible for TBIW-NF, the following documentation must demonstrate that the applicant:

1. Has significant behavioral and/or cognitive problems which are **directly related** to the brain injury;
2. Requires the **essential** services and/or level of reimbursement that this waiver provides in order to prevent institutionalization.

Print Case Manager's name and address in box for return mailing label.

Phone: _____

Applicant:	Start Date:
Recipient ID Number:	Birthdate:
Age:	Age at Onset:
Primary Diagnosis (ICD-9):	Secondary Diagnosis:
PAS Scores:	Behavior:
Orientation:	Self Preservation:
Case Mix:	Risk Status:
☐ Yes ☐ No Applicant has insurance which will cover nursing facility costs	
Applicant is currently a resident of what nursing facility (if applicable)?	
DHS Staff:	Phone:
☐ Approved	☐ Denied
☐ Other:	
☐ Explanation attached	Date:

PART I BEHAVIOR / EMOTIONAL DEFICITS

The following scale is used to assess the frequency of the applicant's behavioral problems. Please write in the scores for behaviors 1.1 to 1.7. Descriptions of the behaviors must be included.

0 Absent	
1 Rarely	Less than once a month
2 Occasionally	At least once a month, but not weekly
3 Frequently	More than once a week, but not daily
4 Daily	On a daily basis
5 Hourly	Continuously throughout the day

1.1 SELF INJURIOUS BEHAVIOR

Engages in deliberate behavior that causes injury or has potential for causing injury to his/her own body. Examples include: self-hitting, self-biting, head-banging, self-burning, self-poking, or stabbing, ingesting foreign substances, pulling out hair, purposeful tipping of wheelchair.

Score: _____ Behavior modification plan utilized? ☐ Yes ☐ No

Describe: _____

_____

1.2 HURTFUL TO OTHERS

Engages in behavior that causes physical pain to other people or animals. Examples include: hitting, biting, pinching, kicking, and inappropriate sexual (physical) contact.

Score: _____ Behavior modification plan utilized? ☐ Yes ☐ No

Describe: _____

_____

1.3 DESTRUCTION OF PROPERTY

Damages, destroys, or breaks things. Examples include: breaking windows, lamps, or furniture, tearing clothes, setting fires, using tools or objects to damage property.

Score: _____ Behavior modification plan utilized? ☐ Yes ☐ No

Describe: _____

_____

1.4 SOCIALLY OFFENSIVE BEHAVIOR

Behavior offensive to others or that interferes with the activity of others. Examples include: spitting, urinating in inappropriate places, stealing, screaming, verbal harassment, bullying, and masturbating in public.

Score: _____ Behavior modification plan utilized? ☐ Yes ☐ No

Describe: _____

_____

1.5 WANDERING

Departs from home unexpectedly. Examples include: leaving the living area for extended periods of time without informing appropriate persons, running away, wandering away while in community.

Score: _____ Behavior modification plan utilized? ☐ Yes ☐ No

Describe: _____

_____

1.6 WITHDRAWAL BEHAVIOR

Excessively avoids others or situations calling for personal interaction to a point where this behavior significantly interferes with participation in normal daily activities. Examples include: refusing to talk to others, remaining in his/her room for inordinate periods of time, repeatedly declining opportunities to recreate with others, extreme passivity which leads to victimization.

LEVEL I BEHAVIOR	Predictable? Yes ✓	Predictable? No ✓	FREQ (1-5)	DUR (1-5)
Self Injurious				
Client exhibits, or without supervision, observation, or redirection would exhibit, behaviors which lead or have the potential to lead to hospitalization because of self-inflicted injury (including those sustained during property destruction, pica, etc.)				
Client exhibits, or without supervision, observation, or redirection would exhibit, behaviors which lead or have the potential to lead to outpatient medical treatment because of self-inflicted injury.				
Client exhibits, or without supervision, observation, or redirection would exhibit, behaviors which lead or have the potential to lead to first aid because of self-inflicted injury.				
Client exhibits, or without supervision, observation, or redirection would exhibit, hitting, pinching, or otherwise attacking self without requiring first aid or medical treatment. This includes pica where it is unclear if physical damage is occurring.				
Physical Injury to Others				
Client exhibits, or without supervision, observation, or redirection would exhibit, behaviors which cause or have the potential to cause someone else to require hospitalization because of client's aggression.				
Client exhibits, or without supervision, observation, or redirection would exhibit, behaviors which cause or have the potential to cause someone else to require outpatient medical treatment because of client's aggression.				
Client exhibits, or without supervision, observation, or redirection would exhibit, behaviors which cause or have the potential to cause someone else to require first aid because of client's aggression.				
Client exhibits, or without supervision, observation, or redirection would exhibit, behaviors such as pinching, hitting, or slapping but no one has needed first aid because of the behavior.				
Destruction of Property				
Client has exhibited, or without supervision, observation, or redirection would exhibit, behaviors causing or having the potential to cause structural damage to the client's residence (i.e. broken windows, holes in walls, etc.)				
Client has exhibited, or without supervision, observation, or redirection would exhibit, behaviors causing or having the potential to cause damage to appliances, electronics, or furniture.				
Client has exhibited, or without supervision, observation, or redirection would exhibit, behaviors causing or having the potential to cause damage to household items (i.e. dishes, lamps, etc.)				
Client has exhibited, or without supervision, observation, or redirection would exhibit, behaviors causing or having the potential to cause damage to personal items (i.e. clothing, books, toys, etc.)				

Describe self injurious behavior:

Actual Frequency Per 24 Hours: _____

Frequency: _____ Duration: _____ Total Time: _____
(of intervention)

Behavior Modification Plan utilized? ☐ Yes ☐ No

Describe physical injury to others behavior:

Actual Frequency Per 24 Hours: _____

Frequency: _____ Duration: _____ Total Time: _____
(of intervention)

Behavior Modification Plan utilized? ☐ Yes ☐ No

Describe destruction of property behavior and specify items damaged:

Actual Frequency Per 24 Hours: _____

Frequency: _____ Duration: _____ Total Time: _____
(of intervention)

Behavior Modification Plan utilized? ☐ Yes ☐ No

LEVEL II BEHAVIORS

1.4 SOCIALLY OFFENSIVE BEHAVIOR

Behavior offensive to others or that interferes with the activity of others. Examples include: spitting, urinating in inappropriate places, stealing, screaming, verbal harassment, bullying, and masturbating in public.

Describe: _____

_____

_____

_____

_____

_____

Frequency Per 24 Hours: _____

Frequency: _____ Duration: _____ Total Time: _____
(of intervention)

Behavior Modification Plan utilized? ☐ Yes ☐ No

1.5 WANDERING

Departs from home unexpectedly. Examples include: leaving the living area for extended periods of time without informing appropriate persons, running away, wandering away while in community.

Describe: _____

_____

_____

_____

_____

_____

Frequency Per 24 Hours: _____

Frequency: _____ Duration: _____ Total Time: _____
(of intervention)

Behavior Modification Plan utilized? ☐ Yes ☐ No

1.6 WITHDRAWAL BEHAVIOR

Excessively avoids others or situations calling for personal interaction to a point where this behavior significantly interferes with participation in normal daily activities. Examples include: refusing to talk to others, remaining in his/her room for inordinate periods of time, repeatedly declining opportunities to recreate with others, extreme passivity which leads to victimization.

Describe (withdrawal): _____

_____

_____

_____

_____

_____

Frequency Per 24 Hours: _____

Frequency: _____ Duration: _____ Total Time: _____
(of intervention)

Behavior Modification Plan utilized? ☐ Yes ☐ No

1.7 SUSCEPTIBILITY TO VICTIMIZATION

Lacks sufficient level of judgement or self-protection ability and/or possesses skill deficits which place him/her at increased risk of neglect, physical harm, emotional distress, sexual or financial exploitation, or monetary loss. Examples include: inappropriately familiar with strangers, unaware of monetary values, inability to recognize risk situations, or insufficient ability to seek assistance.

Describe: _____

_____

_____

_____

_____

_____

Frequency Per 24 Hours: _____

Frequency: _____ Duration: _____ Total Time: _____
(of intervention)

Behavior Modification Plan utilized? ☐ Yes ☐ No

Additional comments: _____

_____

_____

_____

PART 2 COGNITIVE DEFICITS

The following scale is used to assess the applicant's cognitive deficits. Please write in the scores for cognitive deficits 2.1 to 2.5. Descriptions of the cognitive deficits must be included.

0 No problem:	Applicant has intact abilities.
1 Minimal problem:	Problems do not interfere with independence and activities of daily living, but may compromise functioning in complex activities.
2 Mild problem:	Problems do not interfere with independence in routine and familiar situations but may limit independence or mildly impair functioning in complex or unfamiliar activities.
3 Mild to moderate:	Problems limit independence and interfere with functioning in routine and familiar situations. May require supervision for some activities (may be able to stay alone for some periods of time, but cannot live independently).
4 Moderate problem:	Problems limit independence and interfere with functioning in routine and familiar situations, requiring moderate levels of assistance in problem solving situations and at least occasional supervision for safety and guidance.
5 Moderate to Severe:	Problems limit independence and interfere with functioning in routine and familiar situations, requiring maximal assistance in problem solving situations and constant supervision.
6 Severe problem:	Applicant is completely dependent.

2.1 ATTENTION AND CONCENTRATION

Examples include: difficulty sustaining attention, easily distracted; unable to filter out irrelevant information, frequently gets lost in group conversation; reduced arousal, sleepiness.

Score: _____ Describe: _____

_____

_____

_____

_____

2.2 LEARNING AND MEMORY

Examples include: difficulty in organizing or processing information; specific memory deficits - remembering visual information rather than verbal/auditory or vice versa; inability to learn due to short-term memory deficits; problems remembering basic routines (i.e. self-care, chores, ADL's).

Score: _____ Describe: _____

_____

_____

_____

_____

2.3 JUDGEMENT AND PERCEPTION

Examples include: misinterpretation of the actions or intentions of others; easily confused by multiple pieces of information presented at one time; socially inappropriate in verbal communication; unrealistic appraisal of his/her strengths and weaknesses.

Score: _____ Describe: _____

_____

_____

_____

2.4 INITIATION AND PLANNING

Examples include: interprets information literally, concrete thinking; difficulty starting or stopping an action, impulsiveness; slow initiation time; confusion as to where to start solving a problem, unrealistic problem-solving strategies; difficulty in sequencing information; difficulty in knowing when, where and how to ask for help; trouble learning from mistakes as well as successes.

Score: _____ Describe: _____

_____

_____

_____

2.5 COMMUNICATION

Examples include: tangential communication (structure of sentences are correct but irrelevant to the situation or topic); talkativeness; use of peculiar words or phrases; confabulation (making up responses); perseveration (repetition of the same response when it is no longer appropriate); disinhibited choice of words.

Score: _____ Describe: _____

_____

_____

_____

2.6 RANCHO LOS AMIGOS LEVELS OF COGNITIVE FUNCTIONING

☐ I. No Response	The individual appears to be in deep sleep and is completely unresponsive to any stimuli.
☐ II. Generalized Response	The individual reacts inconsistently and nonpurposefully to stimuli.
☐ III. Localized Response	The individual responds specifically but inconsistently to stimulus and may follow simple commands.
☐ IV. Confused-Agitated	The individual is in a heightened state of activity with a severely decreased ability to process information. Behavior is nonpurposeful relative to the immediate environment.

☐ **V. Confused-Inappropriate**	The individual appears alert and responds to simple commands fairly consistently. Agitation which is out of proportion (but directly related) to stimuli may be evident.
☐ **VI. Confused-Appropriate**	The individual shows goal oriented behavior, but is dependent upon external input for direction. Simple commands are followed consistently.
☐ **VII. Automatic-Appropriate**	The individual appears appropriate, goes through daily routine automatically. Has absent-to-minimal confusion but lacks insight.
☐ **VIII. Purposeful-Appropriate**	The individual is alert and oriented. Independence in the home and community has returned. Social, emotional, and cognitive abilities may still be decreased.

PART 3 FUNCTIONAL ASSESSMENT

3.1 DRESSING

- ☐ 0 Can dress without help of any kind
- ☐ 1 Needs and receives minimal supervision or reminding
- ☐ * 2 Needs and receives help from another person to put on clothing
- ☐ * 3 Cannot dress self and is dressed by another person
- ☐ * 4 Is never dressed

3.2 GROOMING

- ☐ 0 Grooms self without help of any kind
- ☐ 1 Needs and receives supervision or reminding
- ☐ * 2 Needs and receives daily help from another person
- ☐ * 3 Is completely groomed by another person

3.3 BATHING

- ☐ 0 Bathes without help of any kind
- ☐ 1 Needs and receives minimal supervision and reminding
- ☐ 2 Needs and receives supervision only
- ☐ 3 Needs and receives help getting in and out of tub
- ☐ * 4 Needs and receives personal help washing and/or drying body
- ☐ * 5 Is completely bathed by another person

3.4 EATING

- ☐ 0 Feeds self without help of any kind
- ☐ 1 Needs and receives minimal supervision or reminding
- ☐ * 2 Needs and receives help in cutting food, buttering bread, arranging food, etc.
- ☐ * 3 Needs and receives partial feeding from another person. Includes observation for choking or inappropriate behavior.
- ☐ * 4 Needs and receives total feeding from another person, tube feeding, or IV feeding

3.5 BED MOBILITY

- ☐ 0 Moves self in bed without any help
- ☐ 1 Needs and receives occasional help form another person to sit up
- ☐ * 2 Always needs and receives help form another person to sit up
- ☐ * 3 Needs and receives help in turning and positioning

* Denotes dependency

3.6 TRANSFERRING

- ☐ 0 Transfers without help of any kind
- ☐ 1 Needs and receive guidance only by presence of another person
- ☐ * 2 Needs and receives physical aid of one person
- ☐ * 3 Needs and receives aid of two persons or a mechanical aid
- ☐ * 4 Remains in bed

3.7 WALKING

- ☐ 0 Walks without help of any kind
- ☐ 1 Needs and receives the help of a device (cane, walker, etc.)
- ☐ * 2 Needs and receives help of one person
- ☐ * 3 Needs and receives help of two persons
- ☐ * 4 Unable to walk

3.8 ORIENTATION

- ☐ 0 Oriented
- ☐ 1 Minor forgetfulness
- ☐ 2 Partial or intermittent periods of disorientation
- ☐ 3 Totally disoriented; does not know time, place, identity
- ☐ 4 Comatose

3.9 BEHAVIOR

- ☐ 0 Behavior requires no intervention
- ☐ 1 Needs and receives occasional staff intervention in the form of cues because the applicant is anxious, irritable, lethargic or demanding
- ☐ * 2 Needs and receives regular staff intervention in the form of redirection because the client has episodes of disorientation hallucinates, wanders within facility, is withdrawn or exhibits similar behaviors. Applicant is resistive, but responds to redirection.
- ☐ * 3 Needs and receives behavior management and staff intervention because applicant exhibits disruptive behavior such as verbally abusing others, wandering into private areas of facility, removing or destroying property, or acting in a sexually aggressive manner. Applicant is resistive to redirection.
- ☐ * 4 Needs and receives behavior management and staff intervention because applicant is physically abusive to self and others. Applicant physically resists redirection.

3.10 TOILETING

- ☐ 0 Uses toilet without help
- ☐ * 1 Needs and receives help to toilet, no incontinence
- ☐ * 2 Occasional incontinence, not more than one a week
- ☐ * 3 Incontinence at night
- ☐ * 4 Incontinent bladder, more than once a week
- ☐ * 5 Incontinent bowel, more than once a week
- ☐ * 6 Incontinent bowel and bladder

3.11 SELF-PRESERVATION

- ☐ 0 Independent
- ☐ 1 Minimal supervision
- ☐ 2 Mentally unable
- ☐ 3 Physically unable
- ☐ 4 Both mentally and physically unable

3.12 SPECIAL TREATMENTS

- ☐ 0 No treatment
- ☐ 1 Tube feedings
- ☐ 2 One or more special treatments

3.13 CLINICAL MONITORING

- ☐ 0 Less than once a day
- ☐ 1 1-2 shifts
- ☐ 2 All shifts

CASE MIX CLASSIFICATION: _____

(From the PAS form Resident Classification System Decision Tree)

PART 4 HISTORY OF PAST PLACEMENTS

PLACEMENT	DATES	REASONS FOR FAILURE

Attachment Checklist

- ☐ Letter of Medical Necessity for Neurobehavioral Hospitalization
- ☐ Current Medical Records with Documentation of Behaviors
- ☐ Current Behavior Modification Plan
- ☐ Insurance Documentation (if needed)
- ☐ Care Plan

Provider Care/Service plans for (if applicable):

- ☐ Adult Day Care
- ☐ Behavioral Programming - Management Plan
- ☐ Extended Cognitive Therapy
- ☐ Independent Living Skills
- ☐ Personal Care Services - MA Home Care Assessment
- ☐ Structured Day Program
- ☐ Foster Care, Residential Care, Assisted Living - TBIW Residential Service Provider Care Plan or county document

Additional Information: _____

_____

_____

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Signature: _____ **Date:** _____

(Please mail this form to the regional CRS. The first page will be returned to you.)

TBI WAIVER APPLICATION SUPPLEMENT
FOR NEUROBEHAVIORAL (NB) HOSPITAL LEVEL APPLICANTS

To be eligible for TBIW-NB, the following documentation must demonstrate that the applicant:

1. Has **severe** behavioral problems which are **directly related** to the brain injury; and
2. Requires the level of services available in a neurobehavioral hospital in absence of the waiver.

Print Case Manager's name and address in box for return mailing label.

Phone: _____

Applicant:	Start Date:
Recipient ID Number:	Birthdate:
Age:	Age at Onset:
Primary Diagnosis (ICD-9):	Secondary Diagnosis:
DHS Staff:	Phone:
☐ Approved Amount: $ per month	☐ Denied
☐ Other:	
☐ Explanation attached	Date:

INSURANCE

Applicant is covered by:

☐ Yes ☐ No Private Health Insurance Name: _____

Policy Number: _____

☐ Yes ☐ No HMO or Prepaid Health Name: _____

Policy Number: _____

☐ Yes ☐ No Medicare

Submit documentation of the following:

- ☐ Insurance will cover neurobehavioral hospitalization
- ☐ Insurance benefits were exhausted on: _____
- ☐ Insurance claim was denied
- ☐ Insurance reimbursed a partial amount: $ _____
- ☐ Insurance reimbursement is unknown

PART I BEHAVIOR / EMOTIONAL DEFICITS

The following scales are used to assess the frequency and the duration of intervention of the applicant's behavioral problems. Please write in the scores for Level I Behaviors on the following chart. Document the actual frequency and duration of both Level I and Level II Behaviors in the narrative.

Frequency:

0	**Absent**	
1	**Rarely**	Less than once a month
2	**Occasionally**	At least once a month, but not weekly
3	**Frequently**	More than once a week, but not daily
4	**Daily**	On a daily basis
5	**Hourly**	Continuously throughout the day

Duration:

1	Thirty seconds or less to redirect applicant
2	More than 30 seconds up to 2 minutes to redirect applicant
3	More than 2 minutes up to 5 minutes to redirect applicant
4	More than 5 minutes up to 10 minutes to redirect applicant
5	More than 10 minutes to redirect applicant

LEVEL I BEHAVIORS

1.1 SELF INJURIOUS BEHAVIOR

Engages in deliberate behavior that causes injury or has potential for causing injury to his/her own body. Examples include: self-hitting, self-biting, head-banging, self-burning, self-poking, or stabbing, ingesting foreign substances, pulling out hair, purposeful tipping of wheelchair.

1.2 HURTFUL TO OTHERS

Engages in behavior that causes physical pain to other people or animals. Examples include: hitting, biting, pinching, kicking, and inappropriate sexual (physical) contact.

1.3 DESTRUCTION OF PROPERTY

Damages, destroys, or breaks things. Examples include: breaking windows, lamps, or furniture, tearing clothes, setting fires, using tools or objects to damage property.

If the applicant exhibits (or without supervision, observation, or redirection would exhibit) Level I behaviors, complete the following table. Review the descriptions under each type of Level I behavior in the table and if applicable, check if the behavior is predictable.

The applicant's behavior is "predictable" if, based on observations and experience with the client, the caregiver can discern under what circumstances the applicant will exhibit the behavioral problem and plan appropriate responses in advance.

The applicant's behavior is "unpredictable" if the caregiver cannot discern under what circumstances the applicant will exhibit the behavioral problem; there is no evident pattern and/or trigger.

Score: _____ Behavior modification plan utilized? ☐ Yes ☐ No

Describe: _____

_____

1.7 SUSCEPTIBILITY TO VICTIMIZATION

Lacks sufficient level of judgement or self-protection ability and/or possesses skill deficits which place him/her at increased risk of neglect, physical harm, emotional distress, sexual or financial exploitation, or monetary loss. Examples include: inappropriately familiar with strangers, unaware of monetary values, inability to recognize risk situations, or insufficient ability to seek assistance.

Score: _____ Behavior modification plan utilized? ☐ Yes ☐ No

Describe: _____

_____

PART 2 COGNITIVE DEFICITS

The following scale is used to assess the applicant's cognitive deficits. Please write in the scores for cognitive deficits 2.1 to 2.5. Descriptions of the cognitive deficits must be included.

0 No problem:	Applicant has intact abilities.
1 Minimal problem:	Problems do not interfere with independence and activities of daily living, but may compromise functioning in complex activities.
2 Mild problem:	Problems do not interfere with independence in routine and familiar situations but may limit independence or mildly impair functioning in complex or unfamiliar activities.
3 Mild to moderate:	Problems limit independence and interfere with functioning in routine and familiar situations. May require supervision for some activities but be able to stay alone for periods of time.
4 Moderate problem:	Problems limit independence and interfere with functioning in routine and familiar situations, requiring moderate levels of assistance and supervision.
5 Moderate to Severe:	Problems limit independence and interfere with functioning in routine and familiar situations, requiring maximal assistance and constant supervision.
6 Severe problem:	Applicant requires constant visual supervision during day and nighttime wake staff.

2.1 ATTENTION AND CONCENTRATION

Examples include: difficulty sustaining attention, easily distracted; unable to filter out irrelevant information, frequently gets lost in group conversation; reduced arousal, sleepiness.

Score: _____ Describe: _____

_____

2.2 LEARNING AND MEMORY

Examples include: difficulty in organizing or processing information; specific memory deficits - remembering visual information rather than verbal/auditory or vice versa; inability to learn due to short-term memory deficits; problems remembering basic routines (i.e. self-care, chores, ADL's).

Score: _____ Describe: _____

_____

2.3 JUDGEMENT AND PERCEPTION

Examples include: misinterpretation of the actions or intentions of others; easily confused by multiple pieces of information presented at one time; socially inappropriate in verbal communication; unrealistic appraisal of his/her strengths and weaknesses.

Score: _____ Describe: _____

_____

2.4 INITIATION AND PLANNING

Examples include: interprets information literally, concrete thinking; difficulty starting or stopping an action, impulsiveness; slow initiation time; confusion as to where to start solving a problem, unrealistic problem-solving strategies; difficulty in sequencing information; difficulty in knowing when, where and how to ask for help; trouble learning from mistakes as well as successes.

Score: _____ Describe: _____

_____

2.5 COMMUNICATION

Examples include: tangential communication (structure of sentences are correct but irrelevant to the situation or topic); talkativeness; use of peculiar words or phrases; confabulation (making up responses); perseveration (repetition of the same response when it is no longer appropriate); disinhibited choice of words.

Score: _____ Describe: _____

_____

2.6 RANCHO LOS AMIGOS LEVELS OF COGNITIVE FUNCTIONING

☐ **I. No Response**	The individual appears to be in deep sleep and is completely unresponsive to any stimuli.
☐ **II. Generalized Response**	The individual reacts inconsistently and nonpurposefully to stimuli.
☐ **III. Localized Response**	The individual responds specifically but inconsistently to stimulus and may follow simple commands.
☐ **IV. Confused-Agitated**	The individual is in a heightened state of activity with a severely decreased ability to process information. Behavior is nonpurposeful relative to the immediate environment.
☐ **V. Confused-Inappropriate**	The individual appears alert and responds to simple commands fairly consistently. Agitation which is out of proportion (but directly related) to stimuli may be evident.
☐ **VI. Confused-Appropriate**	The individual shows goal oriented behavior, but is dependent upon external input for direction. Simple commands are followed consistently.
☐ **VII. Automatic-Appropriate**	The individual appears appropriate, goes through daily routine automatically. Has absent-to-minimal confusion but lacks insight.
☐ **VIII. Purposeful-Appropriate**	The individual is alert and oriented. Independence in the home and community has returned. Social, emotional, and cognitive abilities may still be decreased.

PART 3 ALTERNATIVE WAIVER OR MA HOME CARE ELIGIBILITY

☐ Yes ☐ No Applicant has a diagnosis of a major mental illness which required the completion of Level II screening. (Attach a copy of the Level II.)

☐ Yes ☐ No Applicant is currently receiving waivered services.
If yes, which waiver? ☐ MR/RC ☐ ACS ☐ CADI ☐ CAC

3.1 MENTAL RETARDATION / RELATED CONDITIONS WAIVERS (MR/RC)

☐ Yes ☐ No Did the applicant sustain the brain injury before his or her 22nd birthday?
☐ Yes ☐ No Has the applicant been previously determined to have MR or a RC?
☐ Yes ☐ No Is the applicant now under age 22?

If the applicant is under age 22 and has not had an RC determination, your county's Developmental Disability (DD) unit must determine if the applicant meets eligibility criteria for RC.

The definition of RC is:

1. attributable to condition that is closely related to mental retardation (excludes mental illness, chemical dependency, senility); and
2. likely to continue indefinitely; and
3. results in substantial functional limitations in three or more of the following areas of major life activity:
   a. self-care;
   b. understanding and use of language;
   c. learning;
   d. mobility;
   e. self-direction; or
   f. capacity for independent living.

☐ Yes ☐ No The applicant meets MR or RC criteria. If no, attach documentation from the DD unit.

If yes, an applicant that has MR or an RC must have his/her need for nursing facility (NF) services and NF level of care evaluated. Attach a copy of the evaluation.

Comments: _____

_____

_____

3.2 COMMUNITY ALTERNATIVES FOR DISABLED INDIVIDUALS (CADI) AND MA HOME CARE

If the type of services available or the amount of funding through regular MA or CADI is inadequate to prevent institutionalization, the client may be eligible for the TBI Waiver. Please check off the services that will appear on the initial Service Agreement and those that will be implemented within six months of the start date.

PROPOSED WAIVER CARE PLAN * Services not funded by CADI or MA

Initial	Within 6 months	
☐	☐	Adult Day Care
☐	☐	Assisted Living
☐	☐	Behavioral Programming *
☐	☐	Case Management
☐	☐	Case Management Conversion
☐	☐	Chore Services *
☐	☐	Cognitive Rehabilitation Therapy, Extended *
☐	☐	Companion Services *
☐	☐	Explanation of Findings / Psychological Testing, Extended *
☐	☐	Family Counseling and Training
☐	☐	Foster Care
☐	☐	Home Delivered Meals
☐	☐	Home Health: Aide
☐	☐	Home Health: Nursing
☐	☐	Home Health: OT, PT, Speech, Respiratory Therapies
☐	☐	Homemaker
☐	☐	Medical Supplies and Equipment, Extended
☐	☐	Modifications and Adaptations: Home and Vehicle
☐	☐	Independent Living Skills
☐	☐	Independent Living Skills Therapies *
☐	☐	Night Supervision *
☐	☐	Personal Care Assistant
☐	☐	Residential Care Services
☐	☐	Respite Care
		☐ In-Home
		☐ Out-of-Home
☐	☐	Structured Day Program *
☐	☐	Transportation, Extended (Non-medical) *

Estimated Amount of Care Plan per month: $ _____

☐ Yes ☐ No Does the applicant require only personal care or home health agency services?

☐ Yes ☐ No Does the applicant require only services available under CADI?

Why does the client require the TBI Waiver to avoid institutionalization?

_____

_____

_____

_____

_____

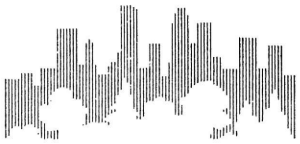
_____

_____

Signature: _____ **Date:** _____

(Please mail this form to the regional CRS. The first page will be returned to you.)

AUGSBURG



C • O • L • L • E • G • E

DATE: 2/16/96

TO: Wendy Walker
6310 - 27th Avenue North, Apt. 119
Crystal MN 55427

FROM: Rita R. Weisbrod, Ph.D.
Chair
Institutional Review Board

RE: Your IRB application "A study of the effectiveness of behavioral programming and the Traumatic Brain Injury Waiver Program: a caregiver's perspective"

Your application falls under categries 2 and 5 for exemption from full IRB review. Hence, I have reviewed it personally and approve it with no conditions. Your IRB approval number is

95 - 46 - 1.

This number should appear on your survey and cover letters.

If there are substantive changes to your project which change your procedures regarding the use of human subjects, you should report them to me by phone (612) 330-1227 or in writing so that they may be reviewed for possible increased risk.

I wish you well in your project!

Hennepin County
An Equal Opportunity Employer
James M. Bonney, County Administrator

January 19, 1996

Dr. Rita Weisbrod
Institutional Review Board Chairperson
2211 Riverside Avenue, Box 186
Minneapolis, MN 55454-1351

Re: Wendy Walker

Dear Dr. Weisbrod:

We are writing to you on behalf of Wendy Walker, MSW graduate student at Augsburg College. Wendy is completing her field placement at our department and she will be conducting a research study of the effectiveness of Behavioral Services for clients with Traumatic Brain Injury. This research will be a valuable source of information for our staff, and we give Wendy our support and thanks for choosing this topic.

Wendy has our permission to use client information gathered from the study. She has been informed of our confidentiality policy and has been practicing under it during her internship. You may call me at 348-3680 with any questions.

Sincerely,

Sue Bulger

Sue Bulger, RN
TBI Waiver Coordinator

Community Health Department

Community-Based Long-Term Care
Health Services Building - Level 3 - MC953
525 Portland Avenue South
Minneapolis, Minnesota 55415

Perceptions of Behavioral Programming Effectiveness And The Traumatic Brain Injury Waiver Program

February 24, 1996

Dear Caregivers,

I am a graduate student working on my Masters in Social Work at Augsburg College in Minneapolis, MN. For my thesis, I am conducting a research study exploring caregiver's perceptions and understanding of behavioral programming provided through Hennepin County's Traumatic Brain Injury Waiver Program. You were selected as a possible participant because you are the identified primary caregiver for an individual currently receiving behavioral management services. This research study has been approved by and is being done in cooperation with Hennepin County Community-Based Long-Term Care Division. Please read this information very carefully.

BACKGROUND INFORMATION:
This research study is being conducted to gather information for my Master of Social Work thesis and provide you with an opportunity to report your perceptions of behavioral program effectiveness and possible recommendations for future programming to Hennepin County Community-Based Long-Term Care Division.

VOLUNTARY NATURE OF THE STUDY:
Your experiences and opinions are important! Your decision to participate in this study is completely voluntary and will not affect your current or future relationship with Hennepin County or Augsburg College.

PROCEDURES AND ANONYMITY:
I am surveying all primary caregivers of individuals who are enrolled in the Traumatic Brain Injury Waiver Program and currently receive behavioral programming services through the Waiver. Your anonymity is protected as Hennepin County Community- Based Long-Term Care Division will be mailing out this questionnaire. Do not put any identifying information including your name or the name of the individual you are caring for on the questionnaire. Completed and returned questionnaires will be kept in a locked file drawer in my home and will not become part of case records and will be destroyed by August 31, 1996.

Only myself and my thesis advisor will have access to the data. Information from this questionnaire will be used for my thesis and will be shared with Hennepin County Community-Based Long-Term Care Division in summarized form only.

RISKS OF BEING A PARTICIPANT IN THIS STUDY:
By completing this questionnaire you may be reminded of feelings or experiences that are associated with the Hennepin county's Traumatic Brain Injury Waiver Program. You may choose to skip questions that are uncomfortable to answer, without risk of being dropped from the research study. For those who have specific questions regarding the Waiver Program a self-addressed stamped postcard has been enclosed to assist you in speaking directly with a case manager. Please mail all postcards separately from completed surveys.

BENEFITS OF BEING A PARTICIPANT IN THIS STUDY:
There are no direct benefits to participating in this reserach study, however it provides an opportunity for caregivers to report their current perceptions of behavioral programming and the possibility to make recommendations for Hennepin County's Traumatic Brain Injury Waiver Program. This feedback will assist Hennepin County Community-Based Long-Term Care Division assess the quality of services provided to young adults utilizing this program.

Thank you for considering to participate in this research study. This questionnaire will take approximately twenty (20) minutes to complete. Once completed please return this questionnaire in the enclosed self-addressed, stamped envelope as soon as possible and no late than March 18, 1996. The completion and return of this questionnaire will indicate your consent to participation in this research study and will also complete your role in this research study.

In two weeks, everyone contacted by this initial letter will receive a follow-up letter with an identical questionnaire requesting your participation in this research project. Please disregard this letter if you have already returned a completed questionnaire or have chosen not to participate in this research study.

If you have any questions regarding this research study please feel free to contact me at (612)-544-2507 or my thesis advisor at Augsburg College, Dr. Sharon Patten, at (612)-330-1723.

Please keep this copy for your records.

Thank you!

Sincerely,

Wendy Walker
Graduate student and principal investigator
#95-46-1

Behavioral Services Questionnaire

Please identify the best answer for each question, then provide comments as indicated.

Background Information

1. How did the client sustain his/her traumatic brain injury? (Please check only one)

_____ automobile accident
_____ fall
_____ toxic reaction
_____ meningitis
_____ don't know
_____ other(please explain)_____
_____
_____

_____ stroke
_____ tumor
_____ aneurysm
_____ encephalitis
_____ motorcycle accident

2. Please identify the client's sex _____ male _____ female

3. What is the client's current marital status?

_____ single
_____ married
_____ separated
_____ divorced
_____ widow/widower
_____ domestic partner

4. What is the client's current age?

_____ 16 to 25 years of age
_____ 26 to 35 years of age
_____ 36 to 45 years of age
_____ 46 to 55 years of age
_____ 56 to 65 years of age
_____ 66 years of age and over
_____ don't know

Primary Caregiver Information

5. Please identify your relationship to the client
_____ family member _____ friend _____ service provider staff
_____ other(explain)_____

6a. Has the client changed his/her living arrangements since enrollment in the Traumatic Brain Injury (TBI) Waiver Program?

_____ Yes _____ No

6b. If yes, please explain _____
_____
_____
_____

7. With whom is the client currently living?
_____ alone _____ with family
_____ with friends _____ group home
_____ other(explain)_____

8. What is the nature of the client's relationship with his/her family?(please explain)
_____
_____
_____
_____

9. Has the client's relationship with his/her family changed as a result of the traumatic brain injury?(please explain)_____
_____
_____
_____
_____

10. **This question to be answered by caregivers who are family or friend. All others please skip to question 11.**

    Have any new means of emotional support been made available to you through the TBI Waiver Program?

    _____ Yes _____ No _____ Don't know

    Please explain_____
    _____
    _____
    _____

Behavioral Services

11. Had the client been involved with any of the following services prior to his/her involvement with the Traumatic Brain Injury(TBI) Waiver Program?

    a. mental health/counseling _____ Yes _____ No _____ Don't know
    b. chemical health intervention _____ Yes _____ No _____ Don't know
    c. other services for behavior issues _____ Yes _____ No _____ Don't know

    If you answered yes to "other services" please identify services.
    _____
    _____
    _____
    _____

12. Is the client currently receiving any behavioral services through the TBI Waiver (that is, behavior professional, behavior analyst, behavior specialist, behavior aide)?

    _____ Yes _____ No _____ Don't know

12b. If yes, please identify the service(s)_____
    _____
    _____
    _____
    _____

Please skip to question 16 unless your answered "Yes" to the above question.

13. Have there been any changes in the client's behavior since the TBI Waiver behavioral services were started?

_____ Yes _____ No _____ Don't know

Please explain _____

_____

_____

_____

_____

_____

14. Are you aware if the client has a behavior plan through the TBI Waiver?

_____ Yes _____ No _____ Don't know

Please skip to question 16 unless you answered "Yes" to the above question.

15. Is the behavior plan being followed by all service providers/caregivers involved with the client?

_____ Yes _____ No _____ Don't know

Please explain _____

_____

_____

_____

_____

_____

_____

16. Does the client's behavior create barriers in any of the following areas?
*** Please comment on your response to all areas identified below.**

a. Social relationships: _____ Yes _____ No _____ Don't know

Please explain_____
_____
_____
_____

b. Housing: _____ Yes _____ No _____ Don't know

Please explain_____
_____
_____
_____

c. Access to health care: _____ Yes _____ No _____ Don't know

Please explain_____
_____
_____
_____

d. Access to the community (e.g., shopping, movies, etc.):
_____ Yes _____ No _____ Don't know

Please explain_____
_____
_____
_____

e. Getting a job: _____ Yes _____ No _____ Don't know
_____ Not applicable

Please explain_____
_____
_____
_____

f. Keeping a job: _____ Yes _____ No _____ Don't know
_____ Not applicable

Please explain_____
_____
_____
_____

g. Other (please explain other barriers not identified above)_____
_____
_____
_____
_____

18. If you identified one or more barriers in the preceding question, have these barriers changed as a result of the behavior services provided through the TBI Waiver Program?

_____ Yes _____ No _____ Don't know

Please explain_____
_____
_____
_____
_____

19. From a caregiver's perspective, in what ways has the TBI Waiver Program been the most helpful to the client? (please explain)_____
_____
_____
_____
_____
_____

20. From a caregiver's perspective, in what ways has the TBI Waiver Program been the least helpful to the client?(please explain)_____

21. Do you have any recommendations for improvement in services offered through the TBI Waiver Program?(please explain)_____

22. Do you have other thoughts or concerns you would like to share regarding the TBI Waiver Program ?(please explain)_____

Thank you very much for participating in this research study. Please do not place your name or other identifying information on the questionnaire. Please return no later than (date)

If you would like someone from the TBI Waiver Program to follow-up with you regarding any questions or concerns, please complete and mail the enclosed self- addressed stamped postcard. Please mail the postcard separately from your completed questionnaire.

#95-46-1

Perceptions of Behavioral Programming Effectiveness and the Traumatic Brain Injury Waiver Program

March 9, 1996

Dear Caregivers,

I am a graduate student working on my Masters in Social Work at Augsburg College in Minneapolis, MN. For my thesis, I am conducting a research study exploring caregiver's perceptions and understanding of behavioral programming provided through Hennepin County's Traumatic Brain Injury Waiver Program. You were selected as a possible participant because you are the identified primary caregiver for an individual currently receiving behavioral management services. **If you have already completed the questionnaire that accompanied the first letter mailed to you please disregard this follow-up letter requesting your participation in this research study.** This research study has been approved by and is being done in cooperation with Hennepin County Community-Based Long-Term Care Division. Please read this information very carefully.

This research study is being conducted to gather information which will provide me with the information for my Master of Social Work thesis and provide you with an opportunity to report your perceptions of behavioral program effectiveness and possible recommendations for future programming to Hennepin County-Community-Based Long-Term Care Division.

I am surveying all primary caregivers of individuals who are enrolled in the Traumatic Brain Injury Waiver Program and currently receive behavioral programming services through the Waiver. Your anonymity is protected as Hennepin County Community-Based Long-Term Care Division will be mailing out this questionnaire. I do not know your name, nor the individual you are caring for. Completed and returned questionnaires will not become part of case records and will be destroyed by August 31, 1996. Information from this questionnaire will be used for my thesis and will be shared with Hennepin County Community-Based Long-Term Care Division in summarized form only.

Your opinions are important! Would you please help in this research study by completing and returning the questionnaire enclosed with this letter. This questionnaire will take approximately twenty (20) minutes to complete. Once completed please return this questionnaire in the enclosed self-addressed, stamped envelope as soon as possible. The completion and return of this

questionnaire will indicate your consent to participation in this research study and will also complete your role in this research study.

Thank you in advance for your participation in this research study. If you are interested in participating in this research study, please complete and return the enclosed questionnaire in the enclosed envelope no late than March 18, 1996.

If you have any questions regarding this research study please feel free to contact me at (612)-544-2507 or my thesis advisor at Augsburg College, Dr. Sharon Patten, at (612)-330-1723 .

If you already completed and returned a questionnaire, thank you for your participation.

Sincerely,

Wendy S. Walker
Graduate student and principal investigator